November 21, 2002

Welcome to FAS Summit 2002!

We are pleased to have you join us for this year's FAS Summit Gathering Resources for Today and Tomorrow. We have shaped the agenda to focus specifically on the development of skills, interventions and strategies that work, and providing information in a way that will help you go back home or to work with a renewed sense of optimism that there are services, interventions, strategies and accommodations that are successful when working with fetal alcohol spectrum disorders.

Over the last four years much has been accomplished across the state of Alaska in improved FASD prevention activities, increased identification and diagnoses of FASD, enhanced and improved training of service providers, and better tracking and data collection increasing the reliability of our FASD prevalence rates. We now know that among states also collecting data on births associated with prenatal exposure to alcohol that Alaska has the highest prevalence rate of FAS at 1.4 births per 1,000.

As we have increased our state's capacity to identify and diagnose FASD—we now have 13 community-based FAS diagnostic teams in Alaska—we are seeing an increase in the number of reports being made to the Alaska Birth Defects Registry for births identified as having "prenatal exposure to alcohol." From fiscal year 2001 to fiscal year 2002 there was a 40% increase in the number of reports made for the conditions associated with potential FASD. Helping to account for this are our diagnostic teams who completed 305 diagnostic assessments from July 2000 to June 2002. Of that number 32, or 10.4% received a diagnosis of FAS, while a total of 303, or 99.3%, had evidence of organic brain damage resulting from prenatal alcohol exposure. This data confirms what we thought we knew—FASD is truly a hidden disability.

As a state we are making progress in addressing FASD. And, the hard work of parents, caregivers, educators, and service providers across the state is making a huge contribution to this progress. Thanks to all of you for your dedication to this issue.

We hope you enjoy your time at the Summit, that you are able to gather many resources to take home, and that you spend time visiting with other participants gaining knowledge, understanding and camaraderie from across the state. Have a great time!

Most sincerely,

L. Diane Casto Program Manager DHSS Office of FAS

· Ajano Casto

Each summer berry buckets across Alaska are dusted off, washed and readied for a new season of gathering berries to use and store for the coming year.

The berry bucket used on this year's Summit material is a symbolic representation of this conference as a time for gathering resources, information and support to use throughout the upcoming year as you work with, live with, or otherwise support individuals with FASD. Much like the store of berries in your freezer, the information provided at this conference will hopefully provide you with new strategies and ideas that will be sustaining in your work. We hope this year's Summit is a time of gathering for you, and that you

leave this conference revitalized with new information, and with a store of resources to use now and in the future.



This publication is funded by the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. Grant #5UD1 SP09198-03

Section 1: General Information Section 2: Thursday Workshops 180 Minute Workshops FAS 101: A foundation of current knowledge, research and School Shouldn't be Painful: Balancing the Sensory, Social, Behavioral and Academic Needs of Students with FASD......47 IDEA: What Parents Need to Know!53 Puberty and Sexuality: Ready or Not Here It Comes!71 90 Minute Workshops Session A Therapeutic Alliances: What Helps and What Hinders From a Consumer and Family Perspective87 Knowledge and Attitudes of Healthcare Professionals Towards Fetal Alcohol Spectrum Disorders89 Prevention Through Education: Getting the FAS message out to youth95 Preventing FASD: Motivating Alcohol-abusing Women into Sobriety107 BRAIN GYM®: Self Care for FASD Individuals, Family, Friends Resource Material 112 Session B Utilizing a Socialization Coach: The Whys and Hows113 Multidisciplinary Diagnosis: The Role of the Physician in a Comprehensive FASD Assessment115 Facing the Final Countdown: The impact of FASD on Alaska's Temporary Assistance Program117 Raising a Child with FAS: Achieving a Positive Mindset127 FASD Education, Intervention and Research Strategies in the

Justice System129

Section 3: Friday Workshops

180 Minute Workshops
Behavior is Communication139
Noisy Diagnoses: Clarity Problems Using the DSM as a tuner in FASD143
90 Minute Workshops
Session A
FAS is Not for Children Only: Strategies for Adolescents and Adults with FAS/E155
BRAIN GYM®: Self Care for FASD Individuals, Family, Friends and Care Providers157
Resource Material160
Risk Management Teams, Restorative Justice and Intercommunication with the FASD Community161
Practical Strategies for School Success for Children with FAS and Alcohol-related Conditions
The Effects of Fetal Alcohol Spectrum Disorders on the Eye and Visual System175
Creating Change: Community Outreach and Networking177
Yoga and Massage for the Special Child181
Session B
The Use of Medication for Treatment of Mental Health Difficulties: An Overview183
Providing Treatment Services to Individuals with FASD185
The Effects of Fetal Alcohol Spectrum Disorders on the Eye and Visual System187
Community Based Support Services for Women Affected by FASD who Exhibit High-Risk Sexual Behavior213
If it's a Standard Deviation, Will it Bite? Understanding your Child's Psychological Assessment215
Receiving a Diagnosis of FAS in your Child: Becoming an Educator and Activist223
S.T.A.R.: An Alaskan School's Response to FASD225
Section 4: Alaska's Comprehensive Project
Index of Workshops256

-Alaska's FAS Summit 2002

Questions?

The registration table will be staffed throughout the two days and will be able to answer any conference related questions.

Brown Bag Lunch Regional Forum on Thursday

This is a optional event that will provide an opportunity for conference attendees to gather by region and discuss activities, issues and concerns about FASD that may be specific to their region. Discussions will be facilitated by local diagnostic team members and innovative FASD project staff, and time will be available for questions and group discussion. Lunch will be provided only to those who pre-registered and prepaid for the Brown Bag Lunch. (Present your ticket at the door.) Everyone is welcome to attend this presentation, even those who did not pre-register. (Bring your own lunch, if you'd like.)

Quilt Raffle

The first ever Family FAS Quilt is on display and raffle tickets will be sold to support the effort of the Anchorage FAS Support Group. Raffle Tickets will be available for \$1.00 each or 6 tickets for \$5.00. The drawing will take place during the Friday Luncheon. To purchase raffle tickets inquire at that Summit registration table.

Resource Room

รัยเกากใน

The Portage Room, located on the landing near the registration table, will be hosting information and resource booths for programs and materials related to FASD.

Cell Phones and Beepers

Please remember to turn them off or on "silent" while you are attending Summit workshops, luncheons, etc.

Continuing Education Credits

The professional associations with which Summit participants are affiliated each have different requirements for CEUs. Summit participants will be provided with a Certificate of Attendance, which may used to get continuing education credits in your field.

The Office of FAS has provided the required documentation to apply for credit approval for:

Teachers (Teacher Education and Certification, D.E.E.D.)

Substance Abuse Counselors (Alaska Commission for Chemical Dependency Professionals Certification)

Continuing education for the FAS/E Summit 2002 is approved by the National Association of Social Workers Alaska Chapter for 12.5 contact hours for Alaska licensed professional social workers, marriage and family therapists, and professional counselors.

Certificates of Attendance

Certificates of Attendance are pre-signed and located in your conference book.

Business Services:

E-mail, Fax, Internet & Photocopies

Available at Kinko's Business Center in the Anchorage Hilton, lobby level, next to elevators. Phone: (907) 677-0444

- ▲ Internet (e-mail) service: \$ 0.20 per minute (\$12.00 per hour)
- ▲ Docking stations are available (to print from a laptop computer)

FAS Summit Info at the Hilton

"Reader boards" are on the lobby level and 2nd floor. These list all events at the Hilton for the day, including Summit events, times, rooms.

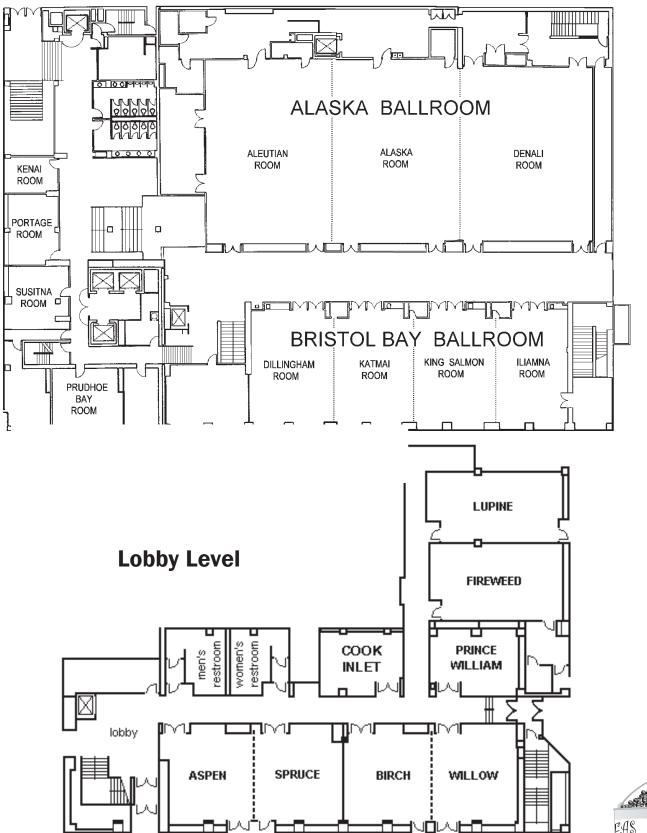
For those staying at the Hilton, turn to "LodgeNet" on Hilton guest rooms TVs to find a list Summit events (schedule, rooms, etc.).

First Aid or Other Emergency:

Call Hilton Security (7018) on hotel phones.

Anchorage Hilton Hotel

Second Floor





Thursday-Day 1

7:30 Registration

8:30 Opening and Welcome

Jay Livey, Health & Social Services, Commissioner L. Diane Casto, Office of FAS

Keynote Presentation by Dr. Edward Riley

Dr. Riley is a leading researcher on the effects of prenatal exposure to alcohol on brain development. Dr. Riley's recent studies consist of functional imaging (fMRI) and correlational studies between brain structural alterations and behavioral changes in an attempt to establish structure-function relationships. Dr. Riley is also Co-Chair of the Steering Committee for the new SAMHSA sponsored FAS Center for Excellence.

10:00 Break

10:30 Youth Panel Presentation: Growing Up with FASD

Young adults from Alaska and from around the country will discuss their experience growing up with, and living with FASD.

11:30 Lunch; Brown bag lunches may be purchased with your registration, or you can do lunch "on your own".

Optional Session

Join others from your region for a facilitated discussion on current projects and activities going on in your community, and participate in a regional planning session. These forums will be facilitated by regional FASD Diagnostic Teams and Grantees.

- 1:00 Break
- 1:30 Workshops-Session A
- **3:00** Break
- 3:30 Workshops-Session B

Friday-Day 2

- 8:30 Workshops-Session A
- 10:00 Break
- 10:30 Workshops-Session B
- 12:30 Summit Luncheon

Video Premier: RuralCAP, an Office of FAS grantee, and a leader in the development of FAS prevention materials, will be debuting it's new video "The Final Score: Winning Against FAS" featuring Alaskans from around the state. Marian Estelle, project director, will highlight the agency's prevention efforts over the recent years.

AWARD CEREMONY

Honoring Alaska's Individual of the Year for excellence in the field of FASD prevention and awareness.

2:30 Break

3:00 – 4:00 Closing Plenary Session – Family Panel

Young adults from the opening session return with members of their support system to talk about what others in their life did to support them in success!



General Information————		
Notes		



Keynote Presentation, Thursday 8:30AM-10:00AM

FASD and Brain Imagery

Presenter

Dr. Edward Riley

Director, Center for Behavioral Teratology San Diego State University

Biography

Edward P. Riley received his Ph.D. in 1974 from Tulane University and since 1988 has been a Professor in the Department of Psychology and the Director of the Center for Behavioral Teratology at San Diego State University, San Diego, CA. His major interest is on the effects of prenatal alcohol exposure on brain and behavior. He is the author of over 170 scientific papers and reviews and has edited the Handbook of Behavioral Teratology. In 2000 he was appointed by the U.S. Secretary of Health as Chair of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects. He was recently appointed as the Co-Chair of the Steering Committee for the new SAMHSA sponsored FAS Center for Excellence. He has served as the President of the Research Society on Alcohol, the Fetal Alcohol Study Group, and the Behavioral Teratology Society. He is currently an Associate Editor of the Journal of Studies on Alcoholism and on the Editorial Board of Alcoholism: Clinical and Experimental Research and the Psychological Record

the Editorial Board of A Notes	Alcoholism: Clinica	l and Experimen	tal Research and the	he Psychological F	Record
Hotes					



FIGURE 11 number 4

december 2001

Using brain imaging to track FAS

by Edward Riley and Sarah Mattson

an educational
newsletter for
people concerned
about fetal alcohol
syndrome (FAS)
and fetal alcohol
effects (FAE)

because the problems we readily see are only the tip of the iceberg



ver since Jones and Smith identified fetal alcohol syndrome in 1973, we have been aware that prenatal alcohol exposure could have a negative effect on normal brain development. One had only to look at the early autopsy reports of infants and children with FAS to see the widespread damage that could occur. However, since most of these reports represented extreme cases of FAS, it was difficult to generalize to the typical case of FAS, let alone cases of FAE. But, about ten years ago we began to work with Terry Jernigan from the University of California San Diego to use magnetic resonance imaging (MRI) to study the living brains of alcoholaffected children in a relatively noninvasive fashion, giving us a better picture of the FAS mind.

Our imaging studies have revealed several brain areas that seem to be particularly affected by prenatal alcohol exposure. For example, the first child that we imaged had a thin corpus callosum, which is the major pathway between the two hemispheres of the brain. The left and right hemispheres coordinate their functions by communicating across the corpus callosum and if this structure isn't functioning appropriately, the two hemispheres can't coordinate effectively. Abnormalities of the corpus callosum have been linked to deficits in attention, reading, learning, memory, planning, decision-making, and psychosocial functioning, all of which are impaired in alcohol-exposed people. The next child that we imaged, to our surprise, was missing the corpus callosum altogether, a condition known as agenesis of the corpus callosum. In this child, the major connection between the two hemispheres of the brain was missing. We have identified three other children with FAS in

San Diego with agenesis of the corpus callosum, and other investigators have also found agenesis in their FAS subjects. However, like the first child that we scanned, most people with FAS and FAE do have an intact

Several brain areas seem to be particularly affected by prenatal alcohol exposure.

corpus callosum, but as in this child, we found that it tends to be smaller, particularly at the front and back parts.

Recently, in collaboration with Elizabeth Sowell and her colleagues at UCLA, we have analyzed the shape and location of the corpus callosum following prenatal alcohol exposure. Again, the corpus callosum was reduced in size, specifically in the back part, but it was also displaced in three-dimensional space. The average location of the corpus callosum for the

CONTINUED ON PAGE 2



iceberg

P.O. Box 95597 Seattle, WA 98145-2597 iceberg_fas@yahoo.com

Iceberg is a quarterly educational newsletter published by FASIS (Fetal Alcohol Syndrome Information Service), a federally recognized 501(c)3 nonprofit, community organization. Iceberg is funded in part by a grant from the Washington State Division of Alcohol & Substance Abuse, Opinions expressed in articles or letters are not necessarily those of FASIS. Subscriptions are available on a prepaid basis (see back page). Letters and articles are welcome. Federal ID No. 91-1559149

FASIS BOARD OF DIRECTORS

Sandra Clarren
Sterling K. Clarren
Jim Fox
Katy Jo Fox
Julie Gelo
Charles W. Huffine
Tracy Jirikowic
Kieran O'Malley
Rose Quinby
Ann P. Streissguth
Tina Talbot
Marceil Ten Eyck
Marilynn Williams

EDITOR

Janice Wilson Vaché

Newsletter design/layout by Dennis Martin Design, 206/363-4500.

All contents copyright
© 2001, FASIS. Permission
to reproduce in whole or
in part is granted with
the stipulation that Iceberg
be acknowledged as the
source on all copies.

Brain imaging

CONTINUED FROM FRONT PAGE

children with FAS and FAE was displaced compared with the control children, with the biggest differences in the part of the corpus callosum closest to the back of the brain. Furthermore, this displacement was related to the children's performance on a verbal learning task.

One area of the brain that we have been particularly intrigued with is a group of subcortical structures known as the basal ganglia. Our studies have shown that the caudate, a part of the basal ganglia is disproportionately reduced in volume in children with FAS and FAE. The caudate is involved in cognitive functions, such as in the ability to shift from one task to another; inhibition of inappropriate behavior; and spatial memory, which are impaired in people with prenatal alcohol exposure. We believe that the reductions in the caudate account for some of the cognitive deficits seen in people with prenatal alcohol exposure. This notion is appealing because the caudate also has extensive connections to the frontal lobes of the brain, which traditionally are thought of as mediating higher cognitive functions.

Finally, we have shown that the cerebellum is also particularly sensitive to prenatal alcohol. The cerebellum or "little brain" is located at the base of the brain. It is involved in both motor and cognitive skills. For example, damage to the cerebellum has been implicated in deficits in learning as well as in balance and coordination, all of which are impaired by prenatal alcohol exposure. We recently found that the volume of the cerebellum was reduced in people with FAS compared with controls, in part replicating our previous reports.

Most recently, we have been looking at new ways of analyzing our brain data to provide additional insights about the damaging effects of prenatal alcohol exposure. Using a technique known as brain mapping, we can now study the whole brain at one time, rather than focusing in on specific brain regions. Elizabeth Sowell and her colleagues have used this brain mapping technique to analyze and compare brain images of people with FAS and FAE and non-alcohol-exposed control subjects. We are showing greater reductions in the brain's white matter, which contains the nerve cells extensions (i.e., axons) that connect nerve cells with each other. These findings were particularly pronounced in the parietal lobe, an area that is involved in visual-spatial processing and the integration of sensory information.

One important point has to be made regarding our studies. We have always examined alcohol-exposed children with and without the facial features of FAS. While our findings are most prominent in the FAS or dysmorphic children, we also find effects in the non-dysmorphic children. While the facial features might provide some indication of brain changes, the absence of these FAS facial features does not preclude alterations in brain and behavior.

What are our current plans and where are we going in the future? We are currently trying to correlate our brain changes with the changes that we see in behavior. For example, how does having a small caudate relate to the ability to shift from one task to another? Our preliminary findings indicate that in children with alcohol exposure histories, the reduction in the size of the caudate predicts overall performance on tests that require the ability to inhibit responding, as well as learn and recall verbal information. In the future we hope to utilize other imaging techniques such as functional MRI (see related article on page 4), where one examines not the size or volume of a particular structure, but rather how that structure functions. Normal size doesn't necessarily mean normal function, and reduced size doesn't always mean abnormal function. fMRI is a powerful technique to examine how the brain is working. We are also

CONTINUED ON PAGE 5

2 | iceberg | december 2001



Using brain imaging

CONTINUED FROM PAGE 3

examining the possibility of using MRI spectroscopy to examine the brains of children with FAS. This technique provides additional information about the functioning of the brain. The use of new technology and refined use of existing techniques will allow us to continue to learn more about how prenatal alcohol affects brain development, what effect this has on behavior, and perhaps push us closer to developing adequate treatment and intervention strategies. •

Notes	



Plenary Session, Thursday 10:30AM-11:30AM

Youth Panel: From The Perspective of Youth

Presenter

Mary Lou Canney, Facilitator

Fairbanks Resource Center for Parents and Children

Abstract

Young adults with FASD from across the state will share their individual experiences and thoughts on how this disability has impacted and continues to impact them through out their lives. Panel members will discuss about some of the biggest challenges they have encountered, and will talk about strategies they use to deal with challenges they may have faced. This plenary session will be open to audience questions.

Notes	



Plenary—————		
Notes		



Closing Plenary Session, Friday 3:00pm - 4:00pm

Family Panel: What Has Worked

Presenter

Mary Lou Canney, Facilitator

VitaFairbanks Resource Center for Parents and Children

Abstract

The same young adults from our opening session will return with family members to talk about solutions, supports and community involvement that helped their family successfully cope with the challenges FASD can present. The goal of this session is to support the idea that one teacher, parent, social service worker or other caring person can make a tremendous difference in the life of a person with FASD if they understand the disability and are willing to work with them differently.

Notes	O	J	



Plenary—————		
Notes		



FAS 101:

A foundation of current knowledge, research and information

Presenter

Maureen Harwood

Abstract

This training will provide an overview of the history of FAS, the impact of prenatal alcohol exposure on the brain and the implications of this damage for behavior and functioning. The presentation will also offer a general overview of FASD diagnostic criteria and the process for assessment. This is an excellent choice for anyone who has had limited exposure to FAS training, or who needs a refresher on the impacts and potential implications of prenatal exposure to alcohol. FAS 101 will prepare participants for more in-depth workshops covering interventions, assessment and system changes in the field of FASD

Notes		



Fetal Alcohol Spectrum Disorders

A Disability of Discovery: Insights on a Brain- Based Disorder

Acknowledgements

- A lot of people know a lot about FASD and more information is being shared everyday. I thank everyone who advances our understanding of this disorder.
- A few examples: Ann Streissguth, Kieran O'Malley, Julie Conry, Fred Bookstein, Diane Malbin, Jan Lutke, Sarah Mattson, Claire Coles, Marilyn Tony, Mary Lou Canney........

Introduction

- What do you know about FAS?What have you heard in the past?
- When you think about FAS comes to mind?

Positive and negative

• What do you hope to learn today?



Myths about FASD

FAS is a childhood disorder, people outgrow it.

FAS is a "more severe" form of ARBD(FAE).

Behavior problems associated with FAS and FAE are the result of poor parenting.

Mothers of children with FAS are young,careless women who aren't concerned about their substance abuse, and drink despite knowing it is bad for them.

Myths about FASD

Nothing works for people with FAS/ARBD.

FAS/ARBD can be passed on genetically.

Children are born affected by alcohol only if a mother drinks early in her pregnancy.

FAS is specific to certain races or communities.

People affected by alcohol can be helped by one agency.

Objectives

- Understand how alcohol changes the brain
- Outline the primary manifestations of FASD
- Outline some secondary outcomes
- Discuss Alaska's approach
- Offer resources



We'll Drink To That

- FASD is found around the world.
 Many societies have rituals and rites of passage that are associated with alcohol consumption.
- There are a number of reasons why people dripk
- After this training you may need someone to talk with someone about FAS. There are many community resources, parent advocates available throughout the State.

Alaskan Consumption

- A National Institute of Health study indicates that the negative impacts associated with alcohol abuse in Alaska cost more that \$500 million per year.
- Over 20,000 Alaskan women of childbearing age have acknowledged that they are heavy drinkers (DHSS, 1997).

Why Should You Know About FAS

- Incidence rates are reported as 1.4 per 1000 live births for FAS and 12.6 per 1000 live births for other prenatal exposure conditions (State of Alaska, 2001).
- Alaska has the highest KNOWN incidence of FAS in the US (State of Alaska, 2000).



Alcohol and Society

- Women and drinking
 How many are drinking and how many plan their pregnancy
- What dads do
- Bigger issues
 Poverty
 Cultural loss
 Socialized violence

Knowledge Is Power

In times of change, learners inherit the earth while the learned find themselves beautifully equipped to deal with a world that no longer exists

Eric Hoffer

What Can Prenatal Alcohol Exposure Do?

- The science of it
- The evolving natural of information
- The excitement



Alcohol As A Teratogen

- Teratogens are substances or conditions that disrupt typical development in offspring as a result of gestational exposure and cause birth defects.
- Alcohol has a direct toxic effect on cells and can produce cell death, thereby causing certain areas of the brain to actually contain fewer cells than normal (Streissguth,1997, p. 58).

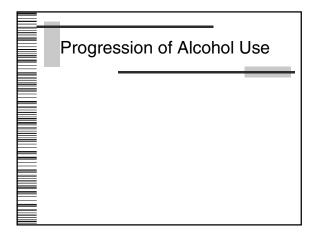
How It Works

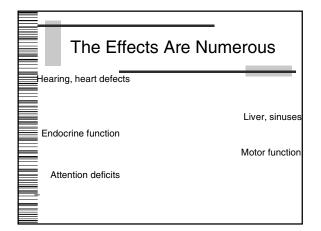
Impacts of alcohol on a fetus depend on a variety of factors:

- •When a mother drinks drinks during her pregnancy
 - ■Pattern and timing
- •The baby's genetic make-up and the mother's
 - How genes and teratogens interact to cause deviant development
- ■How much a mother drinks
 - ■Dose-response

The Puzzle of Genetics







Neurobehavioral Teratogen

Because alcohol produces Central Nervous System (CNS) damage, it is classified as a neurobehavioral teratogen

The neurobehavioral effects of a teratogenic agent such as alcohol can be observed at levels of exposure that produce no physical abnormalities whatsoever (Streissguth, 1997, p. 62).



Alcohol and the Brain

Alcohol exposure appears to damage some parts of the brain, while leaving other parts unaffected.

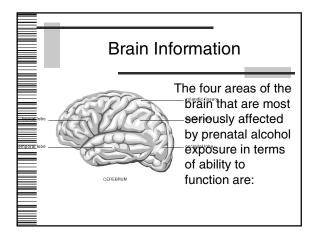
Children with FASD have a whole brain disorder that compounds their ability to communicate their understanding of the world (Kapp, O'Malley, 2001, p. 7).

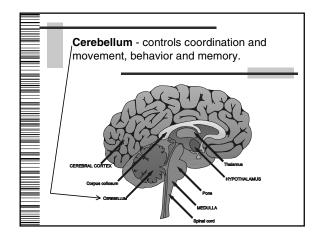
The Fetal Brain Is the Most Vulnerable Organ

The Developing Human, 4th Ed.

How the fetus grows in utero





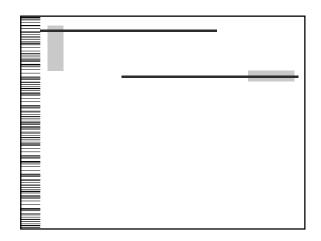


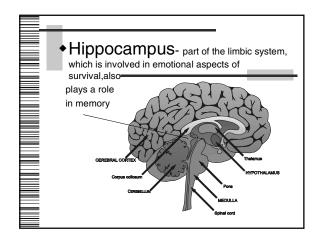
More Brain Stuff

- Basal Ganglia affects spatial memory and behaviors like perseveration and the inability to switch modes, work toward goals, and predict behavioral outcomes, and the perception of time.
- Corpus Callosum passes information from the left brain (rules, logic) to the right brain (impulse, feelings) and vice versa. The Corpus Callosum in an individual with FAS/ARND might be smaller than normal, and in some cases it is almost nonexistent.

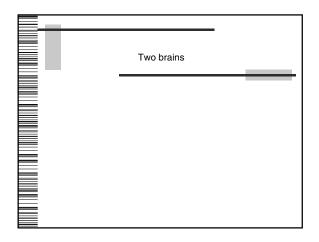


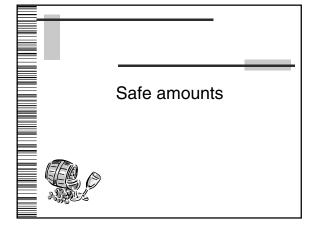












What Is FAS • Medical diagnosis for a permanent condition caused by prenatal alcohol exposure Growth deficiency +Head, height, weight Special pattern of facial features Signs of central nervous system damage



That By Any Other Name.....

- Fetal Alcohol Effects (FAE)
- Partial, probable, or atypical FAS (pFAS)
 People who show most, but not all the classic features of the syndrome
- Alcohol- related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorde (ARND)

Fetal Alcohol Spectrum Disorders

This terms clarifies that intervention needs an understanding of brain-based behavior and of how developmental difference interact with the environment to produce secondary conditions (O' Malley, 2001)

It is not the face or a phenotype that needs the services (Streissguth & O'Malley, 2000, 178)

Fetal Alcohol Spectrum Disorders Subtypes

- Fetal Alcohol Syndrome
- Partial Fetal Alcohol Syndrome
- Alcohol Related Neurodevelopmental Disorders (Kapp, O'Malley, 2001, p. 2)



The Four Digit Code

Four Digit Code (Brain, Alcohol, Growth, Face)
 1234

Static Encehalopathy- non-progressive brain disorder (sentinel physical findings)

This diagnosis in the presence of alcohol exposure do not mean that alcohol is the only cause of the problem. A number of other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth

Neurobehavioral disorder

Primary Disabilities

- Neuromotor skill, sensory processing, and sensory-motor integration
 - Modulating incoming stimuli
 - Sleeping and eating
- Cognition and learning
 - Visual spatial skills, learning, memory
 - Speed of central processing of information
 - Executive functioning
- Speech and language

Processing Differences



- Input
- Integration
- Memory
- Output



Processing Deficits:

- Trouble with Abstract Reasoning
- Impaired Ability to Generalize
- Memory Problems
 No sustainability over time
- Issues in Understanding Time
- Problems with Judgment
- Troubles with Socialization and Skills of Independence

Misunderstanding Abstract Concepts

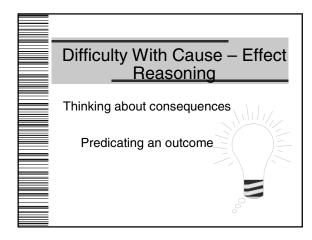
Miss Ideas That Help Our Lives Make Sense



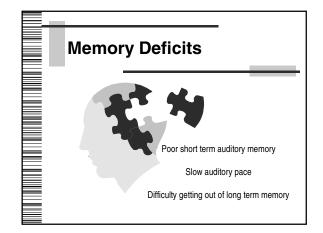
"How am I supposed to know that I do not understand."

Chris Tony

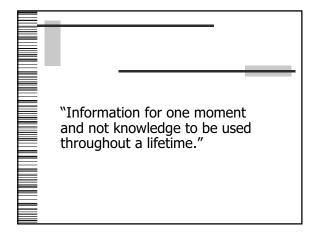


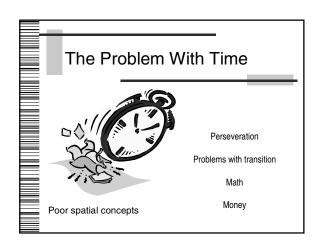


Problems Generalizing Information and Rules Moveable Parts In The Thinking Process Inferential thinking













Challenges With Socialization and Skills of Independence



Problems with the ability to plan, sequence, and feel time pass makes socializing and independent living skills more challenging

Ages and Stages

- Dysmaturity socially and developmentally younger than their chronological age.
- People with FAS often can talk the talk but can't walk the walk.

Secondary Disabilities

"Secondary disabilities are those that a person is not born with, and could presumably be ameliorated (either fully or partially) through better understanding and appropriate interventions."

(Streissguth, Barr, Kogan & Bookstein, 1996, p. 30)



The Secondary Disabilities

- Mental Health issues 90%
- Disrupted school experience- 60%
- Trouble With the Law 60%
- Confinement 50%
- Inappropriate sexual behavior 49 %
- Alcohol and Drug Problems 35%

Secondary Disabilities: other concerns

- Secondary disabilities are more prevalent for individuals diagnosed FAE/ARBD than for individuals with FAS
- Secondary disabilities are more common for affected individuals with higher IQs.

Secondary Characteristics (develop over time from chronic poor "fit" w/environment)

- Fatigue, frustration
- Anxiety, fearfulness
- Rigid, resistant, argumentative
- Flat affect, appear to not care, shutdown, lie
- Poor self concept, feelings of failure and low self esteem
- Isolate- fewer and fewer friends
- Aggressive



Protective Factors

- Living in a stable nurturing home for most of one's life (over 72% of the time)
- FAS diagnosis before the age of 6
- Not a victim of violence
- Being found eligible for DD services
- FAS diagnosis

Working With People With FASD: Ideas for Interventions

Brain Gym, Sensory integration, medicines and other things ...

(Adapted from the work of many incredible people)

So What Do We Do?

The first step to any successful intervention is:

A thorough assessment



See Children As Mysteries

- Not problems
- We solve a mystery we try to get at the answer from different places
- Remember that expectations have to be realistic and appropriate to each child and not to a generalization about FASD (FAS Support Network). There is no phenotype

Try and Reframe Behavior

"Behavior is not the problemit is the outcome of the problem"

Kathryn Shea

_					
Common Misinterpretations					
Behavior	Correct				
۱		Interpretation			
Non compliance	Willful misconduct Stubborn Attention Seeking	Difficulty translating verbal directions Doesn't understand			
Makes same mistakes	Manipulative Willful	Cannot link cause and effect			
Often late	Lazy	Time			
	Poor parenting	Organization			
Out of seat behavior	Willful Pest	Sensory intergration			



Reframe Behavior Interventions

If behaviors are believed to be willful, intentional or the result of emotional problems, then interventions focus on changing behaviors.

If behaviors are understood as reflecting brain differences, then interventions focus on changing environments to prevent frustration and provide support.

Read Evolving Research

Coles (2001) notes that the ADHD observed in alcoholaffected individuals causes more problems with learning new tasks and "in utilizing flexibility in problem solving" than what is seen in the typical ADHD individual (p. 201). The unique expression of ADHD in individuals with FASD is the focus of current research (Coles, 2001, p. 200).

Coles, C. (2001). Fetal alcohol exposure and attention: Moving beyond ADHD.

<u>Alcohol Research & Health, 25</u>, (3), 199-203.

Try Changing How You Do Things

- Give people with FASD longer to answer, develop, achieve
- Reteach skills in every environment they will be used- don't assume
- Use a bouncing chair
- Move from what's wrong with them to what is going on for them



Think of What It Feels Like to Be A Little Out Of Step

Try Differently

- Adjust expectations to reflect the reality of the child's needs and capabilities.
- Think cognitive wheelchair
- Be an interpreter not an interrogator
- Be an investigator on a judge

Goodness of Fit

- Because people do not see them as brain damaged, absent for the alcohol-affected individual is a good "demand- competencies" fit
- A goodness-of-fit "is achieved when individuals are faced with demands from their environment that are appropriate to their abilities" (Richman and Bowen, 1997, p. 104).



Use Concrete Terms and Examples

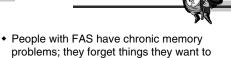
- Use visual, kinesthetic, and language supports (cues) that are basic and easy to understand.
- Always respect each person's age and self-image. Don't treat people like babies

Keep Things Simple

- Keep things short. Overstimulation in an environment or during an activity makes a person with FASD feel anxious and/or unable to think clearly.
- Simplicity harder than it sounds.



Repeat Things



- remember

 Help people by repeating directions, ideas,
- Always repeat it in the same way, in the same tone of voice



Be Specific

- Say exactly what you mean.
- Remember people with FASD are not good at abstracting, generalizing, or inferring so they need clear, concise input.
- Break things into steps.

Be Consistent

- All people working with individuals who have FASD need to approach them the same way. That means using the same words and interventions when giving directions, correcting behavior, or making a plan.
- Coordination between home and school, home and work, etc. is critical for successful functioning.

Use Structure

- Structure gives tasks, activities, and events form. It eliminates confusion. Structure is the invisible "glue" that makes a world make sense.
- Unstructured time is difficult for people with FASD to handle. To keep a person with FASD safe try and avoid activities, places, and times where there is no structure.
- The amount of structure needed for each person with FASD is different.



Establish a Routine

 People with FASD function best when things do not change from day to day. A routine helps people with FASD predict what is coming next. This helps reduce anxiety and makes it easier for alcohol-affected individuals to experience success.



Provide Supervision

- Persons with FASD need ongoing assistance in developing habit patterns of appropriate behavior.
- The amount of supervision changes with the person.

Supervision works!

Keys To Working With People With FASD

- Modify the environment
- Modify expectations
- Think Younger
- Think perpetual innocence
- Exercise the brain
- Use sensory integration techniques
- Rethink, reteach, respect



"At a time when people with disabilities are trying desperately to rise above their disabilities and be recognized for their basic humanity, people with Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), and other prenatal effects of alcohol are still struggling to be understood for the disabilities that they have" (Streissguth, 1998, p.18).

for People with Fetal Alcohol Syndrome TASH Newslotter Sentember Pages 18-2

Alaska's Approach

A federally funded, comprehensive, 5-year approach to:

- Community & systems awareness and education
- Global, targeted, and specific prevention
- Community based diagnostic teams
- Innovative community grants
- Parent leadership
- FAS surveillance

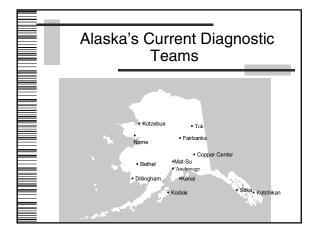
Changing Systems

Change our views about FASD from a behavior problem to a brain based disability with lifelong implications

Share "wisdom of practice" strategies and research results that make a difference

Build-in FAS prevention into our substance abuse programs





Innovative Community Grants

22 community grants targeting either prevention of FAS or improving service delivery systems

Alaska FAS Surveillance Project

Established in 1998 by the State's Section of Maternal, Child, and Family Health, within the Division of Public Health. The Project is part of a collaborative effort with the Centers for Disease Control and Prevention (CDC) and four other states (Arizona, Colorado, New York, and Wisconsin).



How Do Prevalence Rates Help?

- More clearly identify populations for prevention
- Identify communities in need of diagnostic services and resources
- Evaluate prevention efforts
- Frame the issue for legislators and service agencies

Burnout on Both Sides of the Relationship

- Affected Individuals.
 Sometimes people with FASD act out:
 - because they feel that it is better to be bad than to look stupid.
 - Because they are tired and anxious all the time.
 - Because they chronically fail.
 - Because they have experienced a life-long "poor fit".
- Caregivers.
 Sometimes caregivers get tired:
 - Because of the consistent inconsistency observed in there child.
 - Because of negative feedback from others.
 - From having the wrong expectations for their child.

Avoiding Burnout

- Remember people with FASD are not "being bad" - they have brain damage
- Look for resources, ask questions, ask for help
- Remember your strengths and the strengths of the individual with FASD you live or work with
- · But admit your limits and theirs
- Have a plan for times when you both need breaks
- Stick to your plan



Upfront in Hope "Why not spend time, resources, and money upfront in hope rather than later in despair." **Notes:**



Resources related to:

School

- Berg, S., Kinsey, K., Lutke, J., & Wheway, D. (1997). FAS/E and Education: The Art of Making a Difference. FAS/E Support Network of B.C.
- Conry, J. (1998) Teaching Students with Fetal Alcohol Syndrome/Effects: A resource guide for teachers. Victoria: Ministry of Education. Available online at www.bced.gov.bc.ca/specialed/fas/welcome.htm
- Lasser, P. (1999). Challenges and Opportunities: A Handbook for Teachers of Students with Special needs with a focus on Fetal Alcohol Syndrome and partial Fetal Alcohol Syndrome. Vancouver: Vancouver School Board.

General Knowledge

- Berg, S., Kinsey, K., Lutke, J., & Wheway, D. (1995). *A Laymen's Guide To FAS/E. FAS/E Support Network of B.C.*
- Berg, S., Kinsey, K., Lutke, J., & Wheway, D. (1997). So your Child Has FAS/E:What you need to know.
- Kleinfeld, J., Morse, B. & Wescott, S. (Eds.). (2000). Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome. Fairbanks: University of Alaska Press.
- Kleinfeld, J. & Wescott, S. (Eds.). (1993). Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome. Fairbanks: University of Alaska Press.
- Lutke, J. (1997). Spider web walking: Hope for children with FAS Through understanding. In A. Streissguth & J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.* (pp. 181–188). Seattle: University of Washington Press.
- Malbin, D. (1999). Fetal Alcohol Syndrome and Fetal Alcohol Effects: Trying Differently Rather Than Harder. Oregon: FASCETS, Inc.
- Streissguth, A. (1997). Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore: Paul Brookes.

Clinical

- Thackray, H. 2001 Fetal alcohl Syndroem Pediatrics in Review, 22, 2, 47–53
- Malbin, D. (1993). Fetal Alcohol Syndrome, Fetal Alcohol Effects: Strategies for professionals. Center City, MN: Hazelden Educational Materials.
- Olsen, H. (in press). Helping individuals with Fetal Alcohol Syndrome and related conditions: A clinician's overview. In McMahon and Peters (Eds.), *Helping Children with Disorders*. New York: Kluwer Academic/ Plenum.

Legal

- Barnett, C. (1997). A judicial perspective on FAS. In A. Streissguth& J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (pp.134–145). Seattle: University of Washington Press.
- Boulding, D. (2001). Mistakes That I Have Made With FAS Clients. Paper presented at a FAS Biannual Conference-British Columbia . Available from Mr. Boulding at suite 206, 2922 Glen Drive, BC.
- Capron, A. M. (1992). Fetal alcohol and felony. Hastings Center Report, 22, (3), 28–29.
- Center for Disease Control and Prevention (Eds.). (1998). Intervening with children affected by prenatal alcohol exposure. Proceedings of a special Focus Session of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (September 10–11).

- Conry, J., & Fast, D. (2000). *Fetal Alcohol Syndrome and the Criminal Justice System*. Vancouver: British Columbia FAS Resource Society.
- Dagher–Margosian, J. (1997). Representing the FAS client in a criminal case. In A. Streissguth & J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (pp.125–133). Seattle: University of Washington Press.
- Jones, M. (2000). Trouble With the Law. In J. Kleinfeld, B. Morse, & S. Wescott (Eds.), *Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (pp. 193–201). Fairbanks: University of Alaska Press.
- Ladue, R., & Dunne, T. (1997). Legal issues and FAS. In A. Streissguth & J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. (pp.146–161). Seattle: University of Washington Press.

Research

Summit

- Abel, E. (1996). Fetal Alcohol Syndrome: Mechanism to Prevention. Boca Raton:CRC Press.
- Astley, S. & Clarren, S. (1999). *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: The 4-Digit Diagnostic Code*. Seattle: University of Washington Press.
- Band, L. & West, J. (1996). Neuropathology in experimental fetal alcohol syndrome. In H-L.Sphor & H-C. Steinhausen (Eds.), *Alcohol, Pregnancy and the Developing Child* (pp. 103–122). Cambridge: Cambridge University Press.
- Children's Commission (2001, February). *Fetal Alcohol Syndrome: A call to action in B.C.* Victoria: Children's Commission, B.C. 1(800) 859–1441.
- Coggins, T., Friet, T., Morgan, T. (1997). Analyzing narrative productions in older schoolage children and adolescents with Fetal Alcohol Syndrome: An experimental tool for clinical applications. *Clinical Linguistics& Phonetics*. 12, 221–236.
- Coles, C. (2001). Fetal alcohol exposure and attention: Moving beyond ADHD. *Alcohol Research & Health*, 25, (3), 199–203.
- Conry, J., Fast, D., & Loock, C. (1999). Identifying FAS among youth in the criminal justice system. *Journal of Developmental and Behavioral Pediatrics*, 20, (5), 370–372.
- Famy, C., Streissguth, A., & Unis, A. (1998). Mental illness in adults with Fetal Alcohol Syndrome or Fetal Alcohol Effects. *American Journal of Psychiatry*, 155, (4), 552–554.
- Golden, J. (1999). An argument that goes back to the womb: the demedicalization of Fetal Alcohol Syndrome, 1973–1992. *Journal of Social History*, 33, 269–298.
- Hannigan, J, & Abel, E. (1996) Animal models for alcohol-related birth defects. In H-L. Sphor, & H-C Steinhausen, (Eds.), *Alcohol, Pregnancy and the Developing Child*. (pp. 77–192). Cambridge: Cambridge University Press.
- Jones, K., Smith D. (1973). Recognition of the fetal alcohol syndrome in early infancy. *Lancet*, *2*, 999–1001.
- Kerns. K., Don, A., Mateer, C., & Streissguth, A. (1997). Cognitive deficits in non-retarded adults with Fetal Alcohol Syndrome. *Journal of Learning Disabilities*, 30, (6), 685–693
- Kim, K. Osborn, J., & Weinberg, J. (1996). Stress reactivity in Fetal Alcohol Syndrome. In E. Abel (Ed.), *Fetal Alcohol Syndrome: Mechanism to Prevention.* (pp. 215–336). Boca Raton:CRC Press.
- Kronowitz, M. (1991). Fetal Alcohol Syndrome in Alaska: A Monograph. CDC Contract # BD283-91.
- Mattson, S., Goodman, A., Caine, C., Delis, D., & Riley, E. (1999). Executive functioning in children with heavy prenatal alcohol exposure. *Alcohol Clinical and Experimental Research*, 23, (11), 1808–1815.
 - Mattson, S., Jernigan T., & Riley, E. (1994). MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health and Research World*, *18*, (1), 49–52.

- FAS 101 (T01)-
- Mattson, S., & Riley. E. (1995). Prenatal exposure to alcohol: what the Images reveal. Alcohol Health and Research World, 19, 273–278.
- Mattson, S., & Riley, E. (1998). A review of the neurobehavioral deficits in children with fetal alcohol syndrome or prenatally exposed to alcohol. *Alcohol Clinical and Experimental Research*, 22, 279–294.
- National Institute of Alcoholism and Alcohol Abuse (NIAAA). (2000). 10th Special Report to the U.S. Congress on Alcohol and Health: Highlights from current research. U.S. Department of Health and Human Services. www.
- Olson, H., Morse, B., & Huffine, C. (1998). Developmental and Pychopathology: Fetal Alcohol Syndrome and Related Conditions. *Seminars in Clinical Neuropsychiatry*. 3 (4), 262–284.
- Randall, C. (2001) Alcohol and Pregnancy: Highlights from Three Decades of Research. Journal of Studies of Alcohol, 62. 554–561.
- Sphor, H-L, Steinhausen, H-C. (1996). *Alcohol, Pregnancy and the Developing Child*. Cambridge: Cambridge University Press.
- State of Alaska. (2002, Winter). Fetal Alcohol Syndrome Update. Department of Health and Social Services.
- ———(2001). Fetal Alcohol Syndrome prevalence in Alaska: New findings from the FAS surveillance project. *Family Health* Dataline, 7 (1). Special Supplement to 2001 Status Update. Juneau: Department of Health and Social Services
- ————(2000). Fetal Alcohol Syndrome 2000 Status Update: Alaska's Response to Fetal Alcohol Syndrome. Juneau: Department of Health and Social Services.
- ————(1999). Finding the Answers to Tough Questions about Substance Abuse in Alaska. An Annual Report. Juneau: Advisory Board on Alcoholism and Drug Abuse.
- Stratton, K., Howe, C., & Battaglia, F. (1996). *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Washington, D.C.: National Academy Press, Institute of Medicine.
- Streissguth, A. (1994). A long-term perspective of FAS. *Alcohol Health and Research World*, 18, (1), 74–81.
- Streissgith, A., Barr, H., Kogan, J., & Bookstein, F. (1996). Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Seattle: Washington Publication Services.
- Streissguth, A., & Kanter J. (Eds.). (1997). *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. Seattle: The University of Washington Press. Streissguth, A. & O'Malley, K. (2000). Neuropsychiatric implications and long- term consequences of Fetal Alcohol Spectrum Disorders. *Seminars in Clinical Neuropsychiatry*, *5*, (3), 177–190.
- Sulik, K., Johnson, M., Webb, M. (1981). Fetal Alcohol Syndrome: Embryogenesis in a mouse model. *Science*, 214, 936–938.
- Thomas, S., Kelly, S., Mattson, S., & Riley, E. (1998). Comparison of social abilities of children with Fetal Alcohol Syndrome to those of children with similar IQ scores and normal controls. *Alcoholism: Clinical and Experimental Research*, 22, 528–533.



Videos

Preventing and Prevailing: The Challenge of Fetal Alcohol Syndrome.[videotape]. Juneau: RXL Pulitzer. 1 800 344 1432

FAS: *Life Sentence* [videotape]. Films for Humanities and Sciences (Producer). Princeton: New Jersey. 1 800 257 5126

Fetal Alcohol Syndrome and Effect: Stories of Help and Hope. [video tape]. Hazelden 1800328 900 The Development of the Human Brain. [videotape]. Films for Humanities and Sciences (Producer). Princeton: New Jersey. 1 800 257 5126

Learning Disability and Social Skills with Richard Lavoie: Last One Picked First One Picked On. [videotape]. www.pbs.org. call PBS Video toll-free with a credit card (800) 344–3337 mail check or P.O. to PBS Video, 1320 Braddock Place, Alexandria, VA 22314 fax P.O. only (703) 739-5269

Websites

www.hss.state.ak.us/fas/ www.fetalalcohol.com www.niaaa.nih.gov www.washington.edu/fadu/ www.nofas.org www.thearc.org/faqs/fas.html www.cdc.gov/ncbddd/fas



FAS 101 (T01)———		
Notes:		



School Shouldn't be Painful: Balancing the Sensory, Social, Behavioral and Academic Needs of Students with FASD

Presenter

Paula Cook, Special Education Teacher

Lord Nelson School 820 McPhillips Street Winnipeg, Manitoba, Canada, R2X 2J7 Tele: (204) 586-1908 direct line

Fax: (204) 582-6558

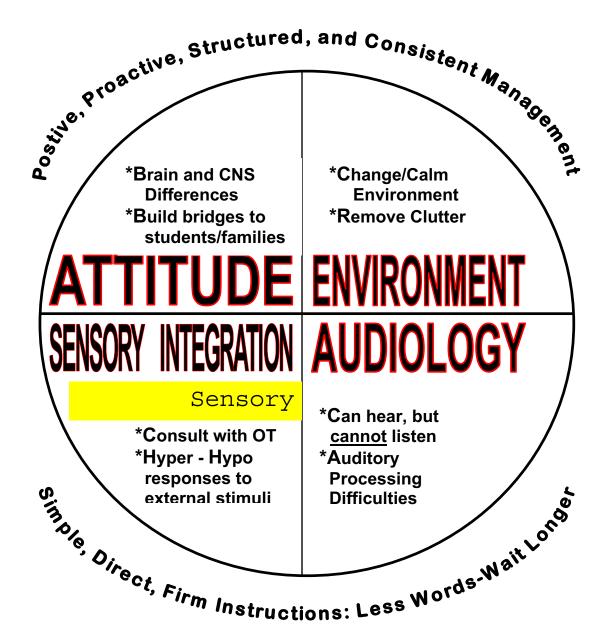
Abstract

For some students with Fetal Alcohol Spectrum Disorders (FASD), school can be a very painful place to be. The implications of physical aggravations on learning, such as hunger and lack of sleep, are well documented and widely accepted. Because students with FASD typically confront learning disabilities, hyperactivity, and inconsistent/uneven social and cognitive development, the pain and discomfort of the effects of FASD on the sensory integration system is often overlooked. Academic performance, social interactions, and behavior are impacted by the physical manifestations of compromised sensory integration systems of students with FASD. This session will investigate some of the manifestations seen in students with compromised sensory integration systems. As a teacher who provides daily and direct educational service delivery to students with FASD, I will share what the students have taught me about the challenges they face daily in school. Often, their stamina and resilience is not recognized or is misinterpreted. Students with FASD bring an abundance of gifts to the classroom, and as teachers, we can support and encourage their unique contributions and nurture productive and healthy environment of our classrooms.

Notes			
ea.			
10.00			



Blending and Balancing Behaviorism with the FAS Model of Behavior Support



© Paula Cook (204) 586-1908 (204) 475-2601 pcook59@shaw .ca



Planning For Multiple Learning Styles

Top	ic:	Date:
	Word Smart Verbal/Linguistic Intelligence	Math Smart Logical/Mathematical Intelligence
	People Smart Interpersonal Intelligence	Self Smart Intrapersonal Intelligence
	Music Smart Musical/Rhythmical Intelligence	Game Smart (Movement) Bodily/Kinesthetic Intelligence
	Art Smart Visual/Spatial Intelligence	Nature Smart Naturalistic Intelligence



Adapted from H. Gardner and Politano Paquin copywrite: Paula Cook (204) 475-2601 or (204) 586-1908

Action Plan

	Name	Name	Name	Name
Continue				
Start				
Do More				
Do Less				
STOP Stop				
Signatures				

copywrite Paula Cook (204) 475-2601 or (204) 586-1908





The woman who slouched down in the seat in front of the bus distressed me. Her hair was matted, her face dirty and though it was cold outside, she was wearing only a flimsy jacket. Hardly the type of jacket adequate for the sub zero temperatures.

"What should I do?"

I wondered. She was so obviously in need, and it was Christmas time, too. Why wasn't there a shelter she could go to? Where were all those agencies and professionals who knew how to deal with these types of people? Couldn't some social worker at least have gotten her a warm coat and maybe a warm place to stay for awhile? I'm was just an ordinary person. I couldn't do anything. Her problems were too much for me.

As I pondered the woman's plight, the bus came to a stop. A young man, poorly dressed, but well groomed, rose to leave. He had gotten off and the bus was already moving before I noticed what he had done. He had slipped off his black knit gloves and laid them on the woman's lap.

Adapted from: Guideposts Magazine. 1991.

Paula Cook (204) 475-2601 or (204) 586-1908



School Shouldn't Be Painful (TO2)———					
Notes					



IDEA: What Parents Need to Know!

Presenter

Theresa Holt, Legal advocate

Disability Law Center of Alaska 3330 Arctic Boulevard #103 Anchorage, AK 99503 (907) 565-1002 tholt@dlcak.org

Abstract

This presentation will provide a general overview of special education law, focusing on the IDEA (Individuals with Disabilities in Education Act). The presentation will provide an overview of the process outlined by the law. It will contain practical information and hints to help parents advocate for their children. A more detailed discussion will be offered on IDEA's provisions for the discipline of special education students. Workshop facilitators will offer in depth information on: suspensions, expulsions, manifestation determinations, functional behavioral assessments, positive behavior intervention plans, and the law as related to weapons or illegal drug offenses, and the parent's and child's rights under IDEA.

Notes			





(800) 478-1234

Bethel Office PO Box 2303 Bethel, AK 99559 543-3357

Anchorage Office 3330 Arctic Blvd. Ste. 103 Anchorage, AK 99503 565-1002 Fairbanks Office 250 Cushman, Ste. 3H FBKS, AK 99701 456-1070

Juneau Office 230 S. Franklin, Ste. 209 Juneau, AK 99801 586-1627



Free Appropriate Public Education FAPE

FREE means education provided at public expense and at no cost to the parents of a child with a disability.

APPROPRIATE is defined as education designed to meet the individual needs of a child with a disability as adequately as the needs of non-disabled students are met.

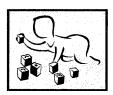
PUBLIC relates to the fact that education should be provided to all children through the use of public funds and it should be provided in the public school environment, not in a segregated setting.

EDUCATION identifies the intent to provide education to all students regardless of the severity of their disability.



IDEA- Individuals with Disabilities Education Act

Early Intervention-Infant Learning Programs-birth to 3 years old



Preschool Services-Local School Districts-3 to 5 years old

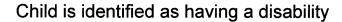


Special Education - Local School Districts - Kindergarten to 21 years old





IDEA PROCESS



Referral or request for an evaluation

Child is evaluated

Eligibility is decided

Child is eligible for IDEA

IEP meeting is scheduled

IEP meeting is held and plan is written

Special education and related services are provided

Progress is measured

IEP is reviewed annually

Re-evaluation every three years



Eligibility Criteria

34 CFR 300.7



- ➤ Ages 3 through 21
- ➤ In one of the following *categories*:
 - ✓ Mental retardation
 - ✓ Hearing impairments including deafness
 - ✓ Speech or language impairments
 - ✓ Visual impairments including blindness
 - ✓ Emotional disturbance
 - ✓Orthopedic impairments
 - **✓** Autism
 - ✓ Traumatic brain injury
 - ✓ Other health impairments
 - ✓ Specific learning disabilities
 - ✓ Deaf/blindness
 - ✓ Multiple disabilities
 - ✓ Developmental delay
- That adversely affects educational performance and as a result, the child needs special education and related services.



Evaluation Procedures

34 CFR 300.532 (b)(1) and (j)



Two purposes for evaluations:

- 1. Determine Eligibility.
- 2. Provide information that directly assists IEP team in determining the educational needs of the child.

Reevaluation is conducted if conditions warrant or if the child's parent or teacher requests . . but at least once every three years. (34 CFR 300.536)



Medical Services

(34 CFR 300.24(b)(4)



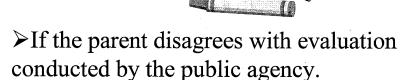
Medical services means services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services.

Federal law does not require medical evaluations to determine eligibility. States may impose a medical evaluation requirement, however, the medical evaluation must be provided at no cost to the parents.



Independent Educational Evaluation (IEE)

34 CFR 300.502



Definition: Evaluation conducted by a qualified examiner who is not employed by the public agency responsible for the education of the child at public expense.

➤IEE must be provided without unnecessary delay or District must initiate a hearing to prove its evaluation is appropriate.

District required to provide information about where an IEE may be obtained.

Completed by a person that meets the District's criteria.



Special Education

34 CFR 300.26(a)



- Specially designed instruction
- At no cost to the parents
- To meet the unique needs of a child with a disability
- Includes:
- Related Services
- Instruction in the classroom, home, hospitals, institutions and other settings.
- Physical Education
- Travel Training
- Vocational Education



Related Services

34 CFR 300.24



Definition: "Transportation and such developmental, corrective, or other supportive services as are required to assist a child with a disability to benefit from special education."

The term includes:

- speech-language pathology and audiology
- psychological services
- physical & occupational therapy
- recreation, including therapeutic recreation
- early identification & assessment
- counseling including rehabilitation counseling
- orientation & mobility services
- medical services for diagnostic or evaluation purposes
- school health services
- social work services
- parent counseling & training

These items are <u>not</u> all the possible items covered (34 CFR 300.14).



E P T e a m

Members of the team

- √ parents
- ✓ regular education teacher of the child, if the child is or may be in the regular education environment
- ✓ special education teacher of the child
- ✓ district representative*
- ✓ someone to interpret evaluation results
- ✓ child, when appropriate
- ✓ others with special knowledge or expertise

* qualified to provide, or to supervise provision of special education, and knowledgeable about the general curriculum and the availability of resources of the public agency

©PACER Center, Inc., 1999



IEP Development



- Process within a process.
- Should be developed in this order:
- 1. Information from Assessment/Evaluation

Drives

2. Present Levels of Educational Performance (or PLEP)

Drives

3. Annual Goal and Short Term Objectives or Benchmarks

Drives

4. Services

Drives

5. Placement



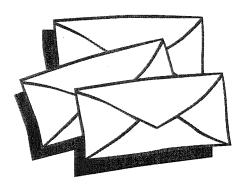


Prior written notice



Written notice - whenever the public ggency proposes or refuses to initiate or change:

- √ identification
- ✓ evaluation
- ✓ educational placement
- ✓ provision of FAPE



©PACER Center, Inc., 1999

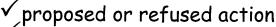




Prior written notice



Content of notice-



- why action is proposed or refused
- ✓ options considered & rejected
- √ all records used by the district in reaching a decision
- ✓ other factors relevant to proposal or refusal
- where parents may obtain procedural safeguards
 - who parents can contact about understanding their rights

Notice must be in understandable language

- ✓ understandable to the general public
- √ in the parent's native language

©PACER Center, Inc., 1999



DISCIPLINE

Suspension vs Expulsion
Weapons or illegal drug offense
Prevention-What can you do?
10 limit on removal from placement
Manifestation Determination Meeting
Functional Behavior Assessment
Positive Behavior Intervention Plan





DISPUTE RESOLUTION

What can be done when parents disagree with their child's school? Parents who disagree with the school district regarding their child's eligibility for special education, evaluations, IEP, placement or discipline have many options for resolving the situation. These include:

- ◆ requesting an IEP meeting,
- writing a letter of disagreement to the school district's Director of Special Education,
- requesting mediation with the school district,
- filing a complaint with the Alaska Department of Education and Early Development,
- filing a complaint with the Office for Civil Rights,
- requesting a due process hearing.





DEA- What Parents Need to Know! (TO3)————————————————————————————————————
Notes:



Puberty and Sexuality: Ready or Not Here It Comes!

Presenters

Cheri Scott

Stone Soup Group/University of Washington FAS Diagnostic Team 2401 E. 42nd Avenue, Suite 202 Anchorage, Alaska 99508 (907) 561-3701 email: cheris@stonesoupgroup

Julie Gelo

University of Washington FAS Diagnostic Team 1512 175th Place S.E. Bothell, Washington 98012 (425) 485-2011 JULIEGELO@aol.com

Abstract

Issues related to sexuality reverberate throughout the lifespan. Puberty is a time of great change for the human body, both physically and emotionally. These complex subjects become even more challenging to understand when an individual has brain differences related to prenatal exposure to alcohol. In this workshop we will discuss the challenges caregivers and service providers face as they try to help children and adolescents understand the process of puberty and learn skills to help them become successful adults well integrated in their community, with stable healthy relationships. We will explore various programs and strategies that can help families as they work with their children toward the goals of independent self-care, good self-esteem, and healthy relationships.

Notes			



Sexuality, Gender, and Human Development



Birth to 3 Years:

- 1. Sex organs are present in both genders.
- 2. Boys can experience erections.
- 3. Girls are susceptible to vaginal infections because of lack of estrogen, which causes the walls of the vagina to be thin and dry.
- 4. Both sexes learn the difference between boys and girls.
- 5. Exploration of own genitals is common.
- 6. Toilet training occurs.
- 7. Curiosity about parents' bodies is evident.
- 8. Gender role-conditioning begins.
- 9. Pleasure is derived from touching, being touched, looking, listening, and sucking.

4 to 8 Years:

- 1. Slight increase in size of genitalia occurs.
- 2. Playing "house" and "doctor" is predictable.
- 3. Engaging in exhibition and observation of others' bodies is common.
- 4. Girls become more interested in fathers and boys in mothers as a way of clarifying their own gender identity.
- 5. Sexual exploration by siblings is more likely.



Sexuality, Gender, and Human Development

- 6. Masturbation is more deliberate.
- 7. Sexual fantasies gradually become more peer-oriented, with kissing games developing.
- 8. The learning of gender roles is taking place.
- 9. Modesty/shame is learned.
- 10. Sex words are being used without their actual meaning being known.
- 11. Sexual activities are learned without names or substantial meaning.

9 to 12 Years:

- 1. Puberty begins here, with first secretions of sexual hormones.
- 2. Growth of pelvic bones, appearance of pubic hair, budding of breasts, and spurt of overall body growth occur.
- 3. In girls, the increased production of estrogen, resulting in an acid PH, makes the vagina resistant to bacterial infection.
- 4. Friendship is strong and exists primarily with members of the same sex.
- 5. Masturbation continues.
- 6. Menstruation, ovulation, and pregnancy become possibilities.
- 7. The probability that sexual activity with others has erotic meaning has increased.
- 8. Sensitivity exists in talking about sex-related matters.
- 9. Gender stereotypes are reinforced.



Sexuality, Gender, and Human Development

13 to 18 Years:

- 1. In girls, breasts continue to grow, underarm and pubic hair increases, and menstruation and ovulation become more regular.
- 2. In boys, genitalia grow, pubic hair increases, sperm is produced, and nocturnal emissions occur.
- 3. Pronounced changes in body configuration and the upsurge in hormone production arouse strong sexual feelings in both sexes.
- 4. Sexually oriented dreams and fantasies become quite dominant, even disturbing.
- 5. Both sexes may masturbate frequently.
- 6. Interest in sexual activity is intense, but not all-consuming in the "normal" teen.
- 7. Sexual exploration, full of erotic meaning, is normal.
- 8. Birth control and HIV prevention become issues.
- 9. Sexual activity is often started without accurate information.
- 10. Pregnancy and AIDS are real possibilities for teens who lack sexual information or think they are not vulnerable.
- 11. Romantic, intensely involved relationships develop between the sexes.
- 12. Romantic and/or sexual relationships are often used to create distance from the family.
- 13. Feelings of guilt often accompany sexual experimentation.
- 14. Gender stereotypes are reinforced and exploited by the advertising industry.
- 15. Venereal diseases, HIV, or other sexual diseases may be transmitted. (These diseases can also occur earlier in life, especially in the sexually abused child.)



Behaviors Related to Sex and Sexuality in Preschool Children

Normal Range	Of Concern	Seek Professional Help
Touches/rubs own genitals when diapers are being changed, when going to sleep, when tense, excited or afraid.	Continues to touch/rub genitals in public after being told many times not to do this.	Touches/rubs self in public or in private to the exclusion of normal childhood activities.
Explores differences between males and females, boys and girls. Touches the genitals, breasts of	Continuous questions about genital differences after all questions have been answered. Touches the genitals, breasts of	Plays male or female roles in an angry, sad or aggressive manner. Hates own/other sex. Sneakily touches adults. Makes
familiar adults and children.	adults not in family. Asks to be touched himself/herself.	others allow touching, demands touching of self.
Takes advantage of opportunity to look at nude persons.	Stares at nude persons even after having seen many persons nude.	Asks people to take off their clothes. Tries to forcibly undress people.
Asks about the genitals, breasts, intercourse, babies.	Keeps asking people even after parent has answered questions at age appropriate levels.	Asks strangers after parent has answered. Sexual knowledge too great for age.
Erections	Continuous erections	Painful erections
Likes to be nude. May show others his/her genitals.	Wants to be nude in public after the parent says "no".	Refuses to put on clothes. Secretly shows self in public after many scoldings.
Interested in watching people doing bathroom functions.	Interest in watching bathroom functions does not wane in days/weeks.	Refuses to leave people alone in bathroom, forces way in to bathroom.
Interested in having/birthing a baby.	Boys interest does not wane after several days/weeks of play about babies.	Displays fear or anger about babies, birthing or intercourse.
Uses "dirty" words for bathroom and sexual functions.	Continues to use "dirty" words at home after parent says "no".	Uses "dirty" words in public and at home after many scoldings.
Plays with feces.	Smears feces on walls or floor more than one time.	Repeatedly plays or smears feces after scolding.
Plays doctor inspecting others bodies.	Frequently plays doctor after being told "no".	Forces child to play doctor, to take off clothes.
Puts something in the genitals or rectum of self or other.	Puts something in genitals or rectum of self or other child after being told "no".	Any coercion or force in putting something in genitals or rectum of other child.
Plays house, may simulate all roles of mommy and daddy.	Humping other children with clothes on.	Simulated or real intercourse with another nude child.



Dimensions of Sexual Development in School-Age Children



- 1. Physical aspects of gender and development.
 - a. Children move from observing to exploring each other's bodies and genitals.
 - b. Games like "Doctor" and "Who can pee the farthest?" permit bodily exploration.
 - c. The child's touching of his or her genitals becomes more intentional; children can use this awareness/skill to help themselves feel good, calm, and/or less anxious.
- 2. Emotional aspects of gender and sexual development.
 - a. Children learn the concepts of modesty and shame.
 - b. During these years, gender identity is well-established.
 - Masturbation is done for comfort, easing tension, and feeling good.
- 3. Moral aspects of gender and sexual development.
 - a. Behavior such as "peeping" or furtive interest in sexually explicit materials (e.g., hidden *Playboy* magazines) reflects children's desire to explore and learn about differences, combined with their emerging understanding that some adults do not approve of nudity and nude pictures.
 - b. Using sexual slang is a common behavior at this age; it is a way to test limits and ask for information about what words are right and wrong to say.
 - c. Behavior is motivated by the child's desire to please peers and gain their approval.
- 4. Social aspects of gender and sexual development.
 - a. Games like "Who can pee the farthest?" give boys an opportunity to explore differences and similarities and to practice competing while being involved in a social activity.



Dimensions of Sexual Development in School-Age Children

- b. Children have learned the concept of "public vs. private," and so masturbation is done privately by normal children.
- c. Sexual slang can be seen as a social behavior, as an attempt at defining the peer group's separateness and cohesiveness by using language that alienates nongroup persons (like adults).
- d. Acquaintanceships give children opportunities to practice behaviors appropriate to their gender.
- e. The needs to be liked and to conform are important in defining the self relative to gender roles.
- 5. Intellectual aspects of sexual development.
 - a. Children still learn by exploring their own and other's genitals/bodies.
 - b. Children become curious about sex and the reproductive process.
 - c. Their curiosity leads them to make comparisons: "Peeping" behavior is a way of gathering new data, and "Who can pee the farthest?" is a game for boys to compare themselves with others. Girls will probably be curious about each other's breast size and date of onset of menstruation. Children in the school years begin to be interested in looking at sexually explicit materials; this is another way they gather new data and compare anatomical differences.

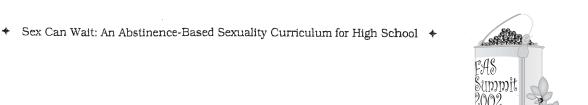


Talking to Your Teen About Sex and Sexuality

Teens want to talk with the important adults in their lives about sex, values and expectations. They do want to know what their parents believe and what their parents experienced when they were young. Teens want and need to be able to get information and honest answers to their questions.

Here are some helpful guidelines for parents and guardians:

- 1. It's all right to be embarrassed—your teen probably is too. Open acknowledgment—"This is difficult for me, but I do want to talk to you about this"—may be all it takes to clear the air and open up discussion.
- 2. Confidently, but not aggressively, state your moral views. A clear and open discussion of differing views may bring teens closer to parental views.
- 3. You may find it helpful to spend some time discussing your values and expectations with your spouse or a close friend before talking with your child. This can help you clarify your values as well as give you some practice with what you want to tell your child.
- 4. You do not have to wait for your teen to ask sexuality-related questions. Honest, open, ongoing discussions of human sexuality can be addressed when families are viewing television, attending social events, planning family pregnancies, reading books, etc.
- 5. Adults are sometimes surprised by a teen's question out of the blue, such as, "How do you know if you're pregnant?" Instead of jumping to conclusions, answer such questions factually and calmly. You may find your teen opening up and explaining why he or she asked the question.





FAMILY HANDOUT

Talking to Your Teen About Sex and Sexuality (continued)

- 6. It is helpful to keep current with new information about sex and sexuality. Read articles from reputable magazines and journals, talk with your doctor or local clinic, attend parent education meetings and utilize personal experience.
- 7. Information about sex doesn't encourage sexual activity. Many parental messages about sex are unspoken. Not talking about sex may give children a sense that because sex is something you can't talk about, it is dirty and forbidden. That may not be the message you want to give. Your own actions and lifestyle probably will have a greater impact on your children's attitudes and behaviors than anything you or anyone else says to them.
- 8. To set limits effectively, parents need to recognize aspects of their teen's development. To establish limits that will work, collaborate on establishing the limits with your teen, be willing to listen and compromise, be consistent in enforcing the rules, recognize and respect the fact that your child is getting older, and acknowledge your teen's need for privacy.
- 9. Accept teens for who they are. Try not to focus on mistakes and shortcomings.
- 10. You can teach teens responsibility for their sexual lives and be available to them without becoming overly involved.
- 11. Like, enjoy and be friends with your teenager. Children grow up fast.
- 12. Discuss the broad spectrum covered by love and sexuality. Talk about tenderness, empathy, compassion, communication and intimacy.





HIV Infection and AIDS Fact Sheet

AIDS Stands For: Acquired Immune Deficiency Syndrome

HIV Stands For: Human Immunodeficiency Virus

Common heard myths about HIV and AIDS:

- ♦ You can transmit HIV through saliva.
- ♦ There is a chance of transmitting HIV through sexual activities that do not involve the direct contact of semen, vaginal secretion, or blood with mucus membranes. Touching stroking, massage, and masturbation cannot transmit HIV. This includes being alone or with a partner.
- Most health care workers contract HIV when the unknowingly treat an HIV infected patient.
- Homosexual men are the most likely to contract HIV.
- There is less risk of contracting HIV if the woman is on the birth control pill.
- Condoms are 100% effective in prevention of HIV.
- ♦ Minorities are more likely to contract HIV than any other people.
- HIV can be transmitted through sharing use of toilets, bathtubs, and other similar facilities.
- Men cannot contract HIV from women. Women can only contract HIV from men.
- There is a cure for AIDS.
- The United States government has a cure for AIDS, but they are hiding it from the public.
- The United States government wants the virus to kill off the type of people that are at risk for it.

Facts about HIV and AIDS:

- ♦ There is no cure for AIDS.
- ♦ Anal intercourse in more likely to allow HIV transmission than vaginal intercourse.
- Oral sex produces a much lower risk for HIV transmission than vaginal or anal intercourse. Yet the risk is very present.
- Transfer of blood and blood products can contract HIV and AIDS.
- Health care workers have contracted HIV and AIDS from their patients.
- Women who have HIV can transmit the virus to their babies.
- People with "high risk" behaviors have a better chance to contract HIV, than people who engage in only safe sexual behaviors.
- People who have a lot of knowledge about HIV and AIDS can still acquire the infection.
- You can reduce your risk of acquiring HIV.

References: HIV and AIDS brochure; Questions about STDs.

Web site: www.plannedparenthood.org



SEXUAL RESPONSIBILITY

RULES FOR SEXUAL EXPRESSION:

THE 4 P'S:

PRIVACY NO SEXUAL EXPRESSION WITHOUT PRIVACY

PERMISSION NO SEXUAL EXPRESSION WITH ANYONE WHO DOES NOT AGREE, OR IS NOT ABLE TO AGREE

PROTECTION ALL SEXUAL EXPRESSION WITH ANOTHER PERSON REQUIRES CONDOM USE

PERSON OVER THE AGE OF 18
SEXUAL EXPRESSION ONLY WITH AN ADULT; NO CHILDREN
ŒVEN IF THE CHILD SAYS YES)



FIVE WAYS TO DESCRIBE A FRIEND

- 1. LIKE TO DO THINGS WITH EACH OTHER.
- 2. CAN TALK TO EACH OTHER ABOUT PERSONAL FEELINGS & EXPERIENCES.
- 3. LIKE TO HELP EACH OTHER.
- 4. LIKE THE PERSON FOR WHO THEY ARE, NOT FOR WHAT THEY HAVE.
- 5. HAVE KNOWN EACH OTHER FOR A LONG TIME AND CAN TRUST EACH OTHER.



MY REPORT

I FEEL..

sad



hurt



afraid







frustrated



embarrassed



WHAT'S IT ABOUT?

money



clothes



friends





food, drink



other



backpack



WHERE?

house





community



care home







car



school







truck



other

bus





SOCIAL SEXUAL EDUCATION RESOURCE LIST

CURRICULUM MATERIALS:

Life Horizons I & II, by Winifred Kempton, James Stanfield Publ., P. O. Box 41058, Santa Barbara, CA 93140, 800-421-6534 (ask for catalogue for complete listings of other good materials).

Being with People, a social skills training program, James Stanfield Publ. Co., same address as above.

Circles, Walker-Hirsch & M. Champagne, James Stanfield Publ. Co., same address as above. A multi-media program designed to teach social distance.

First Impressions, grooming and hygiene program, James Stanfield Co.

Life Sized Instructional Charts, Planned Parenthood of Minnesota-So. Dakota, 1200 Lagoon Ave., Dept. 300, Minneapolis, MN 55408. 612-823-6568. \$172.50

Relationship Series: Friendship, Boyfriend/Girlfriend, & Sexuality, YAI National Institute for People with Disabilities, 460 W. 34th St., New York, NY 10001-2382, each series separately priced. Videos and guides.

Special Education: Secondary FLASH (Family Life and Sexual Health for grades 7-12), J. Stangle, Seattle-King Co. Dept. of Public Health, 1991, \$35.00, Family Planning Publishing, 110 Prefontaine Ave. South, Suite 300, Seattle, WA 98104, 206-296-4902.

STARS (Skills Training for Assertiveness, Relationship-Building and Sexual Awareness)(5th ed., 1998 and **STARS 2** (for children)

A Guidebook for Teaching Positive Sexuality and the Prevention of Sexual Abuse for Children with Developmental Disabilities, Susan Heighway and Susan Kidd Webster, Wisconsin Council on Developmental Disabilities, 1993. Order from Susan Heighway, P. O. Box 5122, Madison, WI 53705. Each curriculum is \$20.00.

I Have a Right to Know (a course on sexuality & personal relationships for people with learning difficulties), Dean Atkinson, Alison Gingell, and Janice Martin, BILD Publications, Plymbridge House, Estover Road, Plymouth, PL67PZ, UK. \$50.00 plus shipping.

Teach-a-Bodies, 3509 Acorn Run, Ft. Worth, TX 76109, 1-888-228-1314, www.teach-a-bodies.com

No How, video on abuse prevention, with persons who are developmentally disabled, Diverse City Press, Box 2003, Angus, ON, L0M 1B0, Canada



REFERENCE MATERIALS:

An Easy Guide to Loving Carefully, Kempton, McKee & Stiggall-Muccigrosso, 1997 (3rd ed.), Simple reproductive health care book. Cost \$20.00, order from Stiggall & Assoc., 21450 Bear Creek Road, Los Gatos, CA 95033

Let's Talk About Health: What Every Woman Should Know, Caryl Heaton, et al., Woman's Health Project, the ARC of New Jersey, 985 Livingston Ave., North Brunswick, NJ 08902. Videotape, audiotape and workbook. 908-246-2525.

Socialization & Sexuality: A Comprehensive Training Gulde for Professionals Helping People with Disabilities that Hinder Learning, Winifred Kempton, 1993. Order from Stiggall & Assoc., 21450 Bear Creek Road, Los Gatos, CA 95033. A basic "encyclopedia" for staff development, and program activities.

POLICIES

Human Sexuality for the Disabled: Putting the Pieces Together, People Building Institute, 1987/1994. Order from Dir. of Social Services, Village Northwest Unlimited, 330 Village Circle, Sheldon, lowa 51201, 712-324-4873.

Human Sexuality Handbook, Gail Brown, et al., 1985/94The Association for Community Living, One Carando Drive, Springfield, MA 01104-3211, 413-732-0531, \$29.00 A comprehensive policy and handbook developed to meet the needs of adults who have developmental disabilities and are receiving residential support.

This list revised and updated 2002



s:			



Therapeutic Alliances: What Helps and What Hinders From a Consumer and Family Perspective

Presenter

Dan Dubovsky, MSW

FAS Specialist CSAP FAS Center for Excellence 1700 Research Blvd. Suite 400 Rockville, MD 20850 301-294-5479

fax: 301-294-5401

e-mail: ddubovsky@northropgrumman.com

Abstract

The essence of a therapeutic alliance is relationship. Unfortunately, in our efforts to provide quality treatment within limited timeframes, we sometimes lose sight of this. The core of this workshop is a discussion by an advocate for an individual with disabilities of what has and has not been helpful throughout their interactions over a 20 year span with systems, programs and people. Recommendations will be offered to improve working relationships between persons with disabilities, families, and professionals and enhance the outcomes of treatment.

Learning Objectives

By the end of this presentation, participants will be able to:

- 1. examine qualities in providers that are viewed by consumers and families as helpful;
- 2. describe what interferes with positive working relationships;
- 3. formulate changes in approach to persons with disabilities and their families that can enhance positive outcomes.

Notes				
_				



Therapeutic Alliances (TAI)—	
Notes	



Knowledge and Attitudes of Healthcare Professionals Towards Fetal Alcohol Spectrum Disorders

Presenter

Andrea Greig

Health Canada, PBH.B National FAS/FAE Team-Division of Childhood and Adolescence Jeanne Mance Building, 9th Floor Room C-961, 1909C2, Tunney's Pasture, Ottawa, Ontario, Canada KIA

State of Alaska

Department of Health and Social Services Division of Alcohol and Drug Abuse Office of Fetal Alcohol Syndrome P O Box 110640 Juneau, AK 99811-0640

Abstract

Survey data are key for the development of educational and policy initiatives with respect to FASD. The results of the first national survey of healthcare professionals in Canada and a recent statewide survey of healthcare professionals in Alaska will be presented. These surveys are important first steps in assessing the current level of understanding of FASD among this population of healthcare professionals in both Alaska and Canada. The data provides a baseline from which we can determine the effectiveness of education, training programs, and information about factors influencing the willingness of healthcare professionals to make FASD diagnoses. Future plans for training, education and awareness in both Alaska and Canada will be discussed.

Notes			





Health Professional Survey Update

Determining Physicians Knowledge & Attitudes about Fetal Alcohol Syndrome

Andrea Greig . Senior Program Consultant FAS/FAE Team Health Canada



Background

Objectives

- To conduct a descriptive survey of the knowledge & attitudes towards FAS
- To develop recommendations, based on findings, to be used to direct policy development and training
- ❖ To utilize survey results as a baseline when monitoring outcomes of policy & initiatives

Methods



- ❖ Participation packages distributed through Canada Post in two waves
 - ➤October 22, 2001
 - ➤ March 21, 2002
- **❖** Follow-up
 - ▶3-week reminder postcard
 - ▶6-week duplicate package
 - ▶9-week reminder postcard
 - ►12-week telephone contact
- ❖ Incentive draw for a Palm Pilot for early return
- **❖** Target response rate of 50 %

FAS Summit 2002	



Questionnaire

General knowledge and attitudes (10 questions; all participants)

❖Prevention Issues

(14 questions; Family Physicians, Obstetricians & Gynecologists; Midwives)

❖Diagnostic Issues

(16 questions; Pediatricians, Psychiatrists)

❖Background Information

(10 questions; all participants)
Web-based or paper-and-pencil options

Preliminary Analysis



Participation Rate

♦Wave 1

>50.1% (N = 1225)

≽Follow-up complete

Results



- ❖97% first heard of FAS more than 4 years ago.
 - > 99% Pediatricians, 94% Psychiatrists, 96% Midwives
- **❖** Most frequent sources of information:
 - ➤ Medical literature (84%)
 ➤ CME activities (54%)

 - Colleagues (56%)
 - ➤ Medical school, residency, fellowship (58%)
- ❖94% agreed that FAS is an identifiable syndrome.
 - > 96% Pediatricians, 92% Psychiatrists, 87% Midwives
- *23% felt the effect of alcohol on fetal development remains unclear.
 - ➤ 21% Pediatricians, 24% Psychiatrists, 33% Midwives



Results



- •94% did not feel that discussing alcohol would frighten or anger patients.
 - ➤ 92% Pediatricians, 97% Psychiatrists, 90% Midwives
- ❖86% did not feel discussing alcohol would deter women from continued treatment.
 - ➤ 83% Pediatricians, 91% Psychiatrists, 85% Midwives
- **❖** Managing problems in the area of alcohol use:
 - >74% agreed that it is the physician's role
 - o 76% that it is the midwife's role
 - o 61% Pediatricians, 56% Psychiatrists, 49% Midwives

Results



- $\ \ \, \ \ \, 30\%$ felt unprepared to deal with alcohol misuse among pregnant women.
 - ➤ 26% Pediatricians, 30% Psychiatrists, 48% Midwives
- **❖ 10%** report asking all pregnant women if they are currently drinking.
 - ➤ all Midwives
- Only 2% report using a screening tool or test for alcohol use with prenatal patients or in assessing risk of misuse among women who report drinking during pregnancy.
 - ➤ all Midwives

Results



Helpful in clinical practice:

- ❖More than 90% identified:
 - ➤ Registry of FAS/FAE specialists available for consultation
 - ➤ Clinical Practice Guidelines
- ❖More than 80% identified:
 - ➤ Literature on the impact of alcohol use
 - ➤ Material or training on FAS/FAE
 - ➤ Referral resources for alcohol problems
 - ➤Internet resources



Results



- **❖** More than 60% identified:
 - Including alcohol use terms on pregnancy checklists
 - ➤ Telemedicine assistance for diagnosis and information
- ❖56% identified training in addiction counselling
 - >45% Pediatricians, 68% Psychiatrists, 77% Midwives
- ❖ 43% identified other specific resources
 - >52% Pediatricians, 21% Psychiatrists, 80% Midwives

Summary



- Physicians and midwives are integral to achieving the ultimate goal of healthy pregnancies and healthy children
- This national survey of health professionals is making visible levels and variations in attitudes and knowledge towards FAS
- This information is essential for the design and development of effective policies and training programs

Standardizing Screening and Diagnosis



- Health Canada has established a committee to recommend National guidelines for screening and diagnosis of FAS/FAE
- Discussion has centered around terminology (FASD), screening tools, diagnostic procedures, surveillance, feasibility of standardized National guidelines
- **❖** In preliminary stages



Canadian Diagnosis Clinics

Clinic	Address	Diagnosis Criteria	Capacity	Waiting List
Asante Centre for FAS	Asante Centre for Fetal Alcohol Syndrome, 22326 (A) McIntosh Ave, Maple Ridge, BC, V2X 3C1	IOM, ICD, 4-digit code	2/week 8/month	none
Sunny Hill Health Centre for Children	4500 Oak Street Vancouver, British Columbia V6H 3V4	IOM, ICD, 4-digit	4/week 16/month	Less than 1 month (infants); 6 months (children)
Children's & Women's Health Centre of BC	4500 Oak Street Vancouver, British Columbia V6H 3V4	IOM, ICD, McKusic (medical genetics)	1/month 12/month (with outreach)	
Craniofacial Clinic (BC)		IOM, ICD, McKusic (medical genetics), 4-digit	1/month	1 year
Toronto Hospital for Sick Children	Toronto Hospital for Sick Children, 555 University Avenue, Toronto, ON M5G-1X8	IOM, Checklist	3-6/month	8 months
Saskatchewan	Alvin Buckwold Child Development Program, Kinsmen Children's Centre, 1319 Colony St, Saskatoon, SK S7N 221	ЮМ	5-6/week 20-24/month	

Canadian Diagnosis Clinics

Newfoundland	Medical Genetics Program, Health Science Center, 300 Prince Phillip Drive, St John's, NF, A1B 3V6	IOM	2/week 8/month	6 months
Winnipeg (MB)	Clinic for Drug and Alcohol Exposed Children (CADEC) Children's Hospital CK 275 840 Sherbrook Street Winnipeg, Manitoba R3A 1S1	IOM and 4-digit code	4/week 16/month	6-9 months
Thompson (MB)		IOM and 4-digit code		
TOTAL CAPACITY			22/week 89/month	



Prevention Through Education: Getting the FAS message out to youth

Presenter

Tiffany Baker

Health & School Educator The Salvation Army Booth Memorial Youth & Family Services 3630 East 20th Anchorage, Alaska 99508

Abstract

Booth Memorial, through its FAS prevention project, has developed FAS prevention curriculum targeting youth. During this session, prevention staff will provide attendees with an overview of the Booth project and curriculum. Presenters will highlight strategies that work with this population, and will discuss the steps toward implementing a youth prevention program in your community. Evaluating prevention effectiveness will be discussed, and prevention staff will share a variety of FASD Resources with participants.

Notes	



Presenting to Adolescents

Effective tools and techniques used when presenting to our youth

Presenters: Tiffany Baker and Joyce Guest

Prevention Through Education

The Developing Adolescent

- · What Erikson thought:
 - He had 8 stages of development
 - Adolescence go through the *identity vs. identity confusion (the fifth stage)*
 - This is where individuals are faced with finding out who they are, what they are all about, and where they are going in life
 - · They are faced with many new roles

• What Piaget thought:

- There were four stages in his theory
- Adolescents enter the final stage -Formal Operational Stage (11 years of age to adulthood)
 - The adolescent reasons in more abstract, idealistic, and more logical ways.
 - They move way beyond concrete experience and think in abstract and more logical terms

FAS Summit 2002	

So What?....

- Why is this important when presenting to adolescents?
 - It is important to understand what they are going through so you can understand how to approach them.
 - When presenting you don't want to lose them you want to keep them focused and interested.
 - Sometimes this can be a difficult task

Who is your target population?

- · Are you presenting to at-risk youth?
- · Are you presenting to non-at-risk youth?
- Are you aware of any learning disabilities?
 - It is important to understand how to present to the different levels of youth
 - You don't want to go over their heads and at the same time you don't want to talk down to them - don't insult their intelligence

At-risk youth

- There are many things to take into consideration when presenting to atrisk youth
 - Their learning capability/disabilities
 - Their environment
 - Their mood
 - Adults at the presentation with you

-03	
FAS Summ 2002) Ît

Non-at-risk youth

- Non-at-risk youth may not be an easier group to talk to. There are different obstacles with this group.
 - The environment may be less restrictive which may lead to more unruliness during the presentation
 - There may be more individuals in the presentation, which could lead to more discipline and less of the material presented

Processing	the	Inform	ation
1 1 0 0 0 0 0 0 1 1 1 9	1110	- 111 O1 11	WI 1011

- · Are there any barriers?
 - Barriers may include:
 - · not enough sleep
 - · bored by the presentation
 - · learning disabilities
 - · lack of supervision
 - · large class size
 - \cdot right before/right after lunch
 - · etc.

Processing the Information

- Other barriers may include:
 - Lack of time
 - Getting off track
 - Getting stuck in one area



Useful Techniques When Dealing with Barriers

- · Liven-up your presentation
 - Asking primary instructor if there are any special needs
 - Use short movies to which the kids can
 - Ask for staff participation or for them to just be present
 - Do multiple classes instead of one big one
 - Have personal notes example 3X5 cards

Useful Tools

- · Outline of the class
- Movies
- Handouts
- · Charts
- · Pictures/Slides

Specific Tools

- - Sacred Trust: Protecting Your Baby Against Fetal Alcohol Syndrome 703.305.2730 Jackie Rodriguez - Program
 - The Final Score: Winning Against FAS -RurAl Cap 1.800.478.7227 Monica Anderson or Marian Estelle
 - The Juneau office has a variety of movies that might suite your needs. You can call 1.877.393.2287 or go to the or website at www.hss.state.ak.us/fas/

FAS Summit 2002



- · Slide Show Presentation
 - Visuals are very important. Get something that will catch their attention, example; the difference between an unaffected brain and an affected brain
- · Charts
 - The Development of a human fetus
 - This helps to explain how important early intervention can be to a pregnant woman and her unborn baby.

Evaluations

- · Pre and Post-test
 - Factors to consider
 - Type of class (See Appendix A, B, and C)
 - Time allowance (# of questions to ask)
 - · Top 5 points (objectives) of presentation
 - FAS is preventable
 - Every time a woman drinks and has sex she increases the risk of having a child with FASD
 - All types of alcohol could cause birth defects
 - Babies born with FAS have multiple and permanent birth defects

Class Evaluation

- Measurements
 - Strongly Agree, Agree, Disagree,
 Strongly Disagree (See Appendix D)
 - Numbers
 - Line Segment

Sec Sec	
FAS Summit 2002	9)
Summit	
2002	10



- · Other Resources
 - Akeela Inc.
 - 907-565-1225 Anchorage location
 - The March of Dimes
 - · www.marchofdimes.com
 - National Office of FAS
 - · www.nofas.org
 - Stone Soup Group
 - · www.stonesoupgroup.org

Reference	ces
. Cantua ale	Tab

 Santrock John W. (2001).
 Adolescence, Eighth Edition. Mc Graw Hill, Boston



Appendix A

Four digit #	PRE or Post Circle one
True and False Put a "T" if you believe the answer to be true or "F" if you believe the an	
1) FAS is a disability due to a mother drinking alcohol during pregnancy.	her
2) The effects of FAS and FAE will go away once an individu adulthood.	al reaches
3) The disabilities experienced by those who have FAE can be severe as those who have FAS.	oe just as
$_{}$ 4) It is OK to drink alcohol in the 3^{rd} trimester.	
5) It is OK for a mother to drink alcohol while she is breastf	eeding.
6) The placenta will protect the baby from alcohol when the drinks during her pregnancy.	mother
7) When women drink alcohol they tend to drink in social set other people.	tings with
8) When a woman drinks during her pregnancy there is little help influence her not to drink.	you can do to
9) It is OK to drink wine during a pregnancy if a doctor OKs	it.
10) FAS is 100% preventable.	



Appendix B

4 Digit #	PRE or POS
Test or False - Parenting Children with F Write "T" if you believe the answer to be TRUE, write "F" if you believe the answer	
1) Alcohol does not effect an unborn baby because the m protects the baby from the ethanol.	other's body
2) Men can play a key role in protecting a child from bein FAS/FAE.	g born with
3) The results of a mother drinking alcohol during her procause a miscarriage.	egnancy can
4) Children effected by FAE can appear to be healthy ba toddlers.	bies and
5) Children with FAS/FAE experience behavioral problem hyperactivity, lying, and some may get into trouble with the law get older.	
6) A parent or caregiver can become frustrated with the effected be FAS/FAE because of the child's behavioral proble	
7) Alcohol related birth defects are easily diagnosed.	
8) FAS children understand the difference between righ	t and wrong.
9) Alcohol effects every woman in the same way.	
10) FAS is 100% preventable.	



Appendix C

Fo	ur Digit #	PRE or POST Circle one
	Multiple Choice - The Final Score: Winning Ag Place and "X" by the best answer provided	ainst FAS
1.	Alaska's number one health problem is:	
	Not enough flushing toilets or running water in Head lice	n homes
	Sexual Transmitted Diseases (STDs)	
	Alcohol Abuse	
2.	Babies born with Fetal Alcohol Syndrome (FAS) have	
	Facial deformities	
	Severe behavior problems	
	Mental retardation	
	All of the above	
3.	What kind of alcohol causes birth defects	
	A shot of whiskey or rum	
	A can of beer or glass of wine	
	A cup of home brew	
	All of the above	
4.	If a couple is sexually active when is it OK to drink al	cohol
	During the daytime	
	Only on the weekend	
	Not drink at all	
	At a party	
5.	Fetal Alcohol Syndrome is	
	Preventable	
	Contagious	
	Inherited	
	Curable	



Appendix D

Evaluation Form

1) I came out of this class with a better understanding of what Fetal Alcohol Syndrome (FAS) is and the dangers of alcohol to an unborn baby.						
Strongly Agree	Agree	Disagree	Strongly Disagree			
2) I understand the di Strongly Agree	fference between FA Agree	S and FAE. Disagree	Strongly Disagree			
3) I now know how alcohol can effect a baby before (s)he is born.						
Strongly Agree	Agree	Disagree	Strongly Disagree			
4) I feel confident talking to my friends and neighbors about the prevention of FAS/FA						
Strongly Agree	Agree	Disagree	Strongly Disagree			
5) I will do what I can to help a woman who is pregnant stay away from alcohol during her pregnancy because I know the dangers of alcohol to an unborn baby.						
Strongly Agree	Agree	Disagree	Strongly Disagree			
6) The speaker presen educational.	ted the material in a	way that was f	un to learn and at the same time			
Strongly Agree	Agree	Disagree	Strongly Disagree			
7) I would recommend	this class to other pe	eople.				
Strongly Agree	Agree	Disagree	Strongly Disagree			
8) Please write down a	nything that you thinl	k the speaker n	nissed during the class.			
9) Please write down a	ny other comments th	nat you think w	ould help the class overall. (Over)			



Prevention Through Education (TA3)————————————————————————————————————
Notes:



Preventing FASD: Motivating Alcohol-abusing Women into Sobriety

Presenter

Candace Shelton, M.S., CSAC, CCS

Clinical Director
Behavioral Health
Native American Connections, Inc.
6965 N. Camio Verde
Tucson, Arizona 85743
(520) 579-3425
email: canshelton@aol.com

Abstract

This workshop will focus on the unique needs of women who are abusing alcohol and having children. The presenter will explore techniques for motivating women into healthier lifestyle choices, what other issues impact women who are drinking and how to empower women and their partners to stop drinking during pregnancy and beyond. The presentation will include a discussion of the characteristics of women who give birth to children exposed to alcohol prenatally and the interventions that can have a positive impact in the prevention of FASD.

Notes		



venting FASD: N es	 CONTON MOMENT	5 Women into	o sourcey (17th	· <i>)</i>
				_



BRAIN GYM®: Self Care for FASD Individuals, Family, Friends and Care Providers

Presenter

Lisa Farber

Certified Brain Gym Instructor **Learning Dynamics** 18560 Rouse Circle Eagle River, AK 99577 (907) 696-0901

email: learningdynamics@alaska.net

Abstract

Brain Gym® is a dynamic tool you can use right away, at home or at work to release stress. These movements simply reconnect the brain hemispheres, allowing a person to move from being "ineffective" to "effective." To be more energetic, think more clearly and make decisions more easily. Learn how to easily decrease stress, be more relaxed and effective by using simple and fun activities.

Notes			
45%			



PACE (POSITIVE, ACTIVE, CLEAR & ENERGETIC)

WATER

Increase water in times of stress.

- creates efficient electrical & chemical action in the brain
- alleviates mental fatigue
- releases stress
- enhances communication & social skills

BRAIN BUTTONS

Find two indentations directly under the collarbone, gently massage. Place other hand over naval. Hold 20-30 seconds, switch hands.

- activates left/right brain hemispheres
- increases oxygen to the brain
- alleviates visual stress

CROSS CRAWL

Can be done sitting or standing. Place right hand on left knee, then left hand on right knee. Repeat 20-30 times, don't rush!

- stimulates right/left brain hemispheres
- improves whole body coordination
- increases ability to cross all midlines (auditory, visual, kinesthetic and tactile)

HOOK UPS

Extend arms out, place backs of hands together, thumbs down; cross one hand over the other, pull into chest. Cross ankles and place tongue on the roof of the mouth.

- increases respiration
- improves focus
- releases stress

H₂O







Source: Brain Gym Handbook by Dr. Paul E. Dennison & Gail Dennison

Learning Dynamics (907) 696-0900

learningdynamics@alaska.net



BRAIN GYM®: A TOOL FOR FAMILIES, FRIENDS AND CARE PROVIDERS

Brain Gym® is a dynamic and fun way to improve all learning skills and behavior for students of any age. Simple, directed movements enhance brain connections to make learning more automatic, moving the learner from the "trying" mode in to a more relaxed state. Developed by Dr. Paul E. Dennison, Brain Gym was created based on an understanding of the interdependence of physical development, language acquisition and academic achievement.

LAZY 8's

Draw a number 8 on its side; start in the middle, directly on the midline. Go up first, keeping head still and using eyes to track. Start small; if easy, then get bigger. If difficult, try a small plus sign instead.



- encourages eye teaming
- enhances ability to cross visual midline
- increases peripheral vision

THINKING CAP

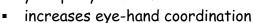
Gently unroll edges of both ears from top to bottom, 4-5 times (until they get hot).

- increases ability to focus
- improves memory
- stimulates ears for "switched-on" hearing



DOUBLE DOODLE

Picture an imaginary line up and down the midline, place hands (with or without pens) in the air or on a board & move them in/out and up/down, making mirror images on either side of the line. Two people can do this activity facing each other. Create any shapes you want.



- improves right/left awareness
- enhances ability to encode/decode



Source: Brain Gym® Teacher's Edition by Dr. Paul E. Dennison and Gail E. Dennison

Learning Dynamics (907) 696-0900

learningdynamics@alaska.net



Brain Gym: A Tool for Families, Friends and Care Providers (TA5)-

Resource Material

Awakening The Child Heart-Handbook for Global Parenting by Dr. Carla Hannaford The importance of play, sound, music and the heart for parenting and life-long joy and learning. Many "how-to's" that can be used immediately!

Brain Gym® and *Brain Gym*® Teacher's Edition by Dr. Paul E. Dennison & Gail E. Dennison These books are packed full of information on basic Brain Gym activities, how to do the movements, the academic and behavioral benefits and variations on each movement.

Brain Gym® Three Day Rotation by Ann RaNae Meders

An easy way to make Brain Gym® an important part of your students' daily routine.

The Brain Train-How To Keep Our Brain Healthy & Wise by Frances Meiser

Discover what foods are good for the brain! Book for all ages.

The Dominance Factor by Dr. Carla Hannaford

This book examines the linkages between the side of the body we favor for seeing, hearing, touching and how knowing this information can benefit the way we learn.

Edu-K for Kids by Dr. Paul E. Dennison & Gail E. Dennison

Prepared for teachers and parents, this book is easily understood and includes step-bystep procedures.

I Am the Child: Using Brain Gym With Children Who Have Special Needs by Cecilia K. Freeman with Gail E. Dennison

An exciting and innovative work that will bring untold riches to children and adults with special needs, as well as those teachers, parents and therapists that work with them.

The Learning Gym by Erich Ballinger

Experience this delightfully illustrated book that has captured the hearts of Europeans since its publication in 1992.

Personalized Whole Brain Integration by Dr. Paul E. Dennison and Gail E. Dennison This book will enable you to "switch on" to a higher level of performance and a deeper level of appreciation for your own uniqueness through an understanding of your brain organization profile. Maximize your potential through simple, directed movements.

Smart Moves by Dr. Carla Hannaford

This easy to understand book explores the nature of intelligence, and how the body/mind processes sensation, emotion and thought. It emphasizes the power of Brain Gym to enhance learning and reduce stress.

Switching On by Dr. Paul E. Dennison

Easy to master techniques to help students integrate right and left brain functions.

"Education in Motion" (videotape) by Dr. Carla Hannaford, Cherokee Shaner, Sandra Zachary and Linda Grinde

A 22 minute introduction to Brain Gym.

"New Paradigm in Reading Instruction" (videotape)

A clear, dynamic and exciting message from the founders of the Foundation for Educational Kinesiology – that education must examine itself and make a paradigm shift and how Brain Gym can play a role in moving into more effective learning.

www.braingym.org

Utilizing a Socialization Coach: The Whys and Hows

Presenter

Dan Dubovsky, MSW

FAS Specialist CSAP FAS Center for Excellence 1700 Research Blvd. Suite 400 Rockville, MD 20850 301-294-5479

fax: 301-294-5401

e-mail: ddubovsky@northropgrumman.com

Abstract

Many individuals affected by prenatal alcohol exposure have some difficulty in social situations. Since the desire of the vast majority of individuals is to have successful social connections, we need to attend to this very important area of life. Unfortunately, our usual attempts at improving socialization frequently do not achieve the results we would like to see. This workshop will examine typical socialization attempts and will consider reasons that many traditional programs are not successful in improving social experiences. We will focus on the concept of using a socialization coach to improve socialization. This is not yet a widespread concept, but is based on the concept and research in job coaching, that has been utilized in vocational programming for some time. We will discuss situations in which a socialization coach may be useful and methods to incorporate this approach into planning.

Learning Objectives

By the end of this presentation, participants will be able to:

- 1. describe the role of a socialization coach for individuals with mental illness;
- 2. examine the differences between the role of a socialization coach and that of a therapist or case manager;
- 3. discuss ways that utilizing a socialization coach can help those with FAS/E increase positive social interactions.

Notes			



lotes	ization Coach		
10103			



Multidisciplinary Diagnosis: The Role of the Physician in a Comprehensive FASD Assessment

Presenter

Dr. Tom Nighswander, M.D., MPH

FAS Statewide Program-Medical Director Office of Fetal Alcohol Syndrome 2105 Otter Street Anchorage, AK 99504 (907) 729-3682

e-mail: nighotte@alaska.net

Abstract

While FASD is a medical diagnosis, the role of the team physician on a FASD diagnostic team is as one part of the team. The comprehensive assessment team is made up of a variety of professionals often including psychologists, parent navigators, speech and language pathologists, occupational therapists, and others. This presentation will provide an overview of the University of Washington's, 4-digit diagnostic model used by teams statewide. This diagnostic 4-digit model includes: assessments of the face, brain, growth and alcohol use by the biological mother. This model allows for a comprehensive profile of individuals tested, allowing for a better understanding of their individual intervention and life skill needs. The panel will focus on the doctor's role and pull members from various community diagnostic teams from across the State to discuss their experience.

Notes		





Facing the Final Countdown: The impact of FASD on Alaska's Temporary Assistance Program

Presenters

Chris Ashenbrenner, Director Angela Salerno, Program Coordinator

Department of Health and Social Services Division of Public Assistance P O Box 110640 Juneau, Alaska 99811-0640 (907) 465-3347 chris ashenbrenner@health.state.ak.us

Abstract

What factors keep families reliant on public assistance? This presentation will provide data and information about "long-term" recipients of Temporary Assistance. Families who had received benefits for at least 40 months were surveyed to discover the factors associated with long-term reliance on Temporary Assistance. The study explored personal and systemic issues, including: demographics, family characteristics, education, employment, and barriers to employment, such as, substance abuse, mental health issues and domestic violence. Could the lack of success in employment for some individuals be related to dealing with the hidden effects of FASD? This presentation will begin to answer the questions of which families are more likely to achieve self-sufficiency, which will require extended financial support and what barriers need to be addressed to help this population be successful.

otes			
40			



University of Alaska Anchorage

State of Alaska
Department of Health and Social Services
Division of Public Assistance

Institute for Circumpolar Health Studies

Facing the Final Countdown: What is the Impact of FASD on the Temporary Assistance Program?

November 2002



Chris Ashenbrenner, DPA Director Angela Salerno, Project Coordinator Brian Saylor, Principal Investigator Beth Sirles, Co-Principal Investigator Curt Lomas, ICHS Project Coordinator



Presentation Objectives

In this presentation you will learn:

- The recent history of Welfare Reform and the context for serving public assistance recipients.
- The challenges to clients and DPA brought about by the lifetime limit on welfare henefits
- Some of the reasons why people leave welfare or stay on long-term.
- Our best information on the impact of FASD on our clients.
- The service responses designed to assist people with challenges to employment.

National Welfare Reform in the 1990s

Personal Responsibility and Work Opportunity Reconciliation Act of 1996

- End of entitlement: "Temporary Assistance for Needy Families" (TANF) replaces AFDC
- Block grants to states and tribes based on historical AFDC funding
- Benefit time limits
- Work requirements

	*1.	
	1 10 X	
1		
305	83% ·	
	(2)	
120cm		
	-11	



Welfare Reform in Alaska

1996: State Welfare Reform Legislation Enacted

- Alaska Temporary Assistance Program (ATAP) replaces AFDC and JOBS
- © Five-year time limit with limited extensions
- Work requirements
- Work incentives increased



4

The Alaska Temporary Assistance Program: <u>Outcomes to Date</u>

Caseload has fallen dramatically: Average monthly Temporary Assistance and Native TANF caseloads for fiscal year 2001: 7,000 families

> 39% lower than the average monthly caseload for FY 1997 (the last year before the implementation of welfare reform)

48% below the historic high of 13,164
 AFDC families in April 1994

5

What do we know about our welfare "leavers?"





Research reveals that welfare "leavers" have different characteristics than "stayers:"



- Most leavers were younger females with small families.
- Leavers were more likely to hold permanent, fulltime jobs and to have higher hourly wages.



- People with serious health problems or disabilities were less likely to leave welfare.
- Leavers were more likely to have at least a high school education.

7

Alaska The Temporary Assistance Program: <u>Challenges</u>

- One third of welfare leavers return to the program within two years.
- Those who remain on the program often have serious impediments to self-sufficiency.
- These "long-term" recipients make up an increasingly large percentage of the caseload.

8

The Alaska Temporary Assistance Program: <u>Challenges</u>

- July 2002 was the first month families in Alaska began to exceed the 60-month time limit for receiving Temporary Assistance.
- While many families will transition off welfare, some will require additional assistance beyond 60 months.
- State law allows exemptions from the 60-month time limit for adults in specific categories.



The Alaska Temporary Assistance Program: <u>Challenges</u>

60-Month Time Limit Exemptions

- Victims of domestic violence
- Adults who are physically or mentally unable to perform gainful activity
- Adults who are providing care for a family members who is experiencing a disability
- Families experiencing hardship

10

The Alaska Temporary Assistance Program: <u>Challenges</u>

60 Month Time Limit Exemptions

Hardship

- Hardship means that a family is experiencing severe or extraordinary barriers to employment and, due to circumstances beyond their control, is in need of additional months of assistance. There are three categories of hardship exemption:
 - Disaster
 - Children at risk of placement outside the home
 - Lack of success at employment

11

The Alaska Temporary Assistance Program: <u>Challenges</u>

60-Month Time Limit Exemptions

Lack of success at employment

- The recipient complies with the Family Self-Sufficiency Plan and is doing everything possible to become self-supporting, but cannot earn wages sufficient to leave Temporary Assistance. Examples of situations that could qualify include but are not limited to:
 - Diagnosed medical or mental health conditions that act as an impediment to employment for which care has been prescribed by a licensed medical professional;
 - Diagnosed functional limitations or impairments that act as an impediment to employment and take into consideration such problems as literacy level, learning or developmental disability or other brain disorders.



The Alaska Temporary Assistance Program: <u>Challenges</u>

60 Month Time Limit Exemptions

©To date, 527 families have reached their 60-month limit.

Of those families 53% have received a benefit extension.

18% have been denied.

29% declined or withdrew.

13

The Alaska Temporary Assistance Program: <u>Challenges</u>

60 Month Time Limit Exemptions

Extension reasons include:

 Domestic Violence 	6%
 Substance abuse 	6%
。Limited English	7 %
Child at risk	9%
 Disabled relative 	10%
 Learning disability 	10%
Physical health	19%
 Mental health 	19%
 Other employment limitation 	25%
。 Incapacity	44% 14

What are the characteristics of longterm recipient families, and how can we help them reach self-sufficiency?





- Informal research reveals that up to 10% of adult, long-term recipients may be impacted by FASD.
- Because of lack of awareness or early diagnosis, the true number is impossible to gage.

16

Facing the Final Countdown: A Study of Long-Term Recipients

Study Objectives

- ODiscover factors associated with long-term reliance on welfare
- Identify challenges faced by families as they attempt to achieve self-sufficiency
- © Gather information to inform effective policy and service responses

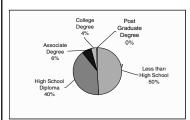
17

Facing the Final Countdown: A **Study of Long-Term Recipients**

Study Methodology

- Study Population Of the 781 families identified as "long-term" (those who had received at least 41 months of Temporary Assistance), a total of 373 adults were interviewed.
- Survey Methods A survey contractor conducted by telephone. Interviews were conducted in the spring of 2000. The survey response rate was 33%.
- Data Sources The data set used for analysis was a combination of survey data and Division of Public Assistance administrative data.

<u>Study Findings</u> *Educational Attainment*



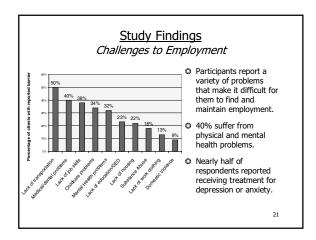
Long-term participants have low educational achievement. Half have not completed high school.

19

Study Findings Employment

Work Status	N	Percent of Respondents
Ever Employed	363	97%
Employed between 7/1/00 - 6/30/01	206	55%
Employed when interviewed	131	35%
Another adult worked 7/1/00 - 6/30/01	60	16%
Subsistence activities	73	20%

Long-term participants work when they can, but employment is unstable. Only a third are employed year-round. Their average wage is \$8.57.





Study Conclusions

- As the Temporary Assistance caseload has fallen during the past five years, the character of the caseload has changed. Many of the remaining recipients face challenges in the areas of physical and mental health, low educational achievement and limited work experience. This is a very vulnerable population.
- At the same time, this is a resilient population. Most single mothers work at least part of the year. Most would rather work than be on welfare. Many have taken steps to complete their education.
- It is essential to provide the supports necessary for the transition from welfare to work. This may be increasingly difficult because the population remaining on Temporary Assistance is likely to require more sophisticated and intensive interventions to help them prepare for financial independence.

22

Service Responses

Self-sufficiency and wellness planning

Case management

Screening and assessment

©Referrals to specialized treatment

Ongoing monitoring

Services for advancement and retention

2

Service Responses

Collaboration with community partners

- Medical community
- Mental health providers
- DFYS
- · Department of Labor
- · Private service providers







For More Information

Chris Ashenbrenner, Director

Angela Salerno, Project Coordinator
Division of Public Assistance

PO Box 110640 – Juneau AK 99811
907-465-3200

www.hss.state.ak.us/dpa

•		Π



Raising a Child with FAS: Achieving a Positive Mindset

Presenter

Kathleen Tavenner Mitchell, MHS, LCADC

Program Director/National Spokesperson National Organization on Fetal Alcohol Syndrome (NOFAS) 216 G Street, NE Washington, DC 20002 (202) 785-4585 email: Mitchell@nofas.org

Abstract

This workshop will explore viewing individuals with Fetal Alcohol Syndrome (FAS) from a circular, rather than a linear perspective. The nature and behaviors of individuals with FAS will be related to principles from spiritual teachings. We tend to focus on the deficits of individuals with FAS; we will explore the most common deficits as assets. Lessons learned will be incorporated into daily steps for developing a positive way of being and living.

Notes		



Raising a Child with EAS (TRA)—		
Raising a Child with FAS (TB4)— Notes		



FASD Education, Intervention and Research Strategies in the Justice System

Presenter

Carol Comolli, Ph. D.,
Education Coordinator
Gastineau Human Services
5597 Aisek Street
Juneau, AK 99801
(907) 780-3013

Abstract

Adults with FAS are critically underserved and typically become involved with the justice system. While this is unfortunate, it also provides an opportunity to identify adults with FAS and provide them with appropriate educational accommodations. This population offers an opportunity to enhance current research on FAS. Further, this population can contribute to the research goal of building a database from which to refine and quantify our definition and assessment of FAS. This presentation will suggest strategies for intervention, accommodation and research.

Notes			



- I. FAS adults as critically underserved and typically involved with the justice system.
- A. What can be done to diagnose and accommodate FAS adults involved in the justice system?
- 1. Basic screening for learning difficulties incorporating portions of the following: Development *Test of Visual-Motor Integration, Detroit Test of Learning Aptitudes, Jordan Oral Screening Test, Minnesota Test for Differential Diagnosis of Aphasia, Motor Free Visual Perception Test and The Southern California Sensory Integration Test.*
 - a. An example of a completed diagnostic screening analysis with **suggested accommodations** will be available during the presentation.
 - 2. General FAS Diagnostic Evaluations.
 - a. Checklists for user friendly FAS screening
 - b. User-friendly check lists for documenting adult behaviors, general life skills and academics.
 - c. Linguistic and communicative behaviors to observe and document.
 - 3. Research: Strategies and Opportunities
 - a. Without reliable data, research is not possible. Incarcerated adults provide an opportunity to contribute valuable data for research on FAS in adults and are in a setting where their needs can be accommodated.
 - (1). They are a monitored population, so accurate records are available and tracking is possible.
 - b. If we develop easy-to-use checklists of behaviors, we can document and share our findings to enhance research on adults with FAS
 - c. In their structured setting, individual educational programs can be developed and implemented to address the specific needs of the FAS adult.



Handout #1 Sensor-Motor Checklist/ Suggested Accommodations (Note: Some individuals with FAS/E have excellent motor skills, while others have significant problems with gross and fine motor skills)

Tactile Sensation	No	Yes
Interested in and enjoys physical activity		
Has the strength to move, balance and handle materials		
Develops patterns of action using the body alone		
Shows coordination of thought and physical activity		
Dislikes washing skin or hair		
Becomes irritable when touched		
Craves being touched		
Strong preferences for certain types of clothing		
Anxious to wash hand after contact with sand, paint, etc.		
Auditory Sensation	No	Yes
Overly sensitive to sounds		
Requires repeated verbal instructions		
Easily distracted by sounds/noises		
Confuses direction of sound		
Tends to speak loudly and make loud noises		
Has diagnosed hearing loss		
Olfactory and Oral Sensation	No	Yes
Notices the environment by smell		
Oversensitive to certain smells		
Ignores strong odors		
Has difficulty discriminating odors		
Strong preferences for certain types of food (hot, cold crunchy, spicy)		
Avoids certain textures of food		
Always chewing on pencils, toothpicks, cigarettes, etc.		



Visual Sensation	No	Yes
Has diagnosed visual problem		
Has trouble keeping eyes on object		
Difficulty following moving objects with eyes		
Distracted by visual stimuli		
Sensitive to light		
Rubs eyes, gets headaches or eyes water when reading		
Muscle Tone and Coordination	No	Yes
Poor posture		
Weaker than normal for age and size		
Stronger than normal for age and size		
Grips objects too tightly		
Grips objects too weakly		
Tires easily		
Seems accicent prone		
Seems clumsy		
Frequently trips or bumps into things		
Changes hands during activities		
Has difficulty manipulating small objects		
Avoids sports		

Suggested Accomodations:

- Encourage the development of keyboarding skills
- Consult a physical or occupational therapist for activities to improve strength and coordination
- Encourage participation in physical activities



Handout #2Cause and Effect Thinking/Memory and Suggested Accommodations

An FAS Individual may experience difficulty with the following:	No	Yes
Understanding consequences		
Generalizing behavior from one setting to another		
Predicting outcomes of different behaviors in new settings		
Has a rigid and egocentric notion of what is fair		
Retaining and using information		
Utilizing sequences of information		
Following through on instructions from others		
Using effective strategies to recall memory on short term		
Using effective strategies to recall memory on longer term		
Making effective use of lists		
Can fill in blanks in sentences with appropriate words		
Can highlight or summarize information to be remembered		
Can use reference resources effectively		
Can remember steps in a procedure		
Can remember and deliver a message to another (accurately)		
Can payigate from one place to another without getting lost easily		

Suggested Accommodations:

- Use hints or prompting to help the individual to remember details
- Teach new strategies for remembering (lists, notes on calendars)
- Teach strategies for setting schedules and being able to follow them (accurately writing out a plan on a daily basis)
- Use multi-sensory approaches to giving instructions (say it, write it down, etc.)



Handout #3 Language Use and Suggested Accommodations

Expressive Language	No	Yes
Articulates sounds clearly		
Uses age appropriate vocabulary		
Uses complete statements or thoughts when talking		
Uses language in a variety of ways (to reason, to predict, to project or imagine)		
Responds appropriately to a variety of question types		
Interacts appropriately with peers in a social setting		
Effectively asks questions to clarify instructions or directions		
Demonstrates age-appropriate verbal telephone skills		
Responds to questions in an appropriate amount of time		
Can give specific details when asked for an explanation or description		
Receptive Language		
Enjoys conversation		
Can follow verbal instructions		
Understands idioms and multiple meanings		
Understands humor		
Understands that a change in vocabulary does not necessarily mean a change in the content of a message		
Actively listens to others and responds to ideas		
Makes associations and generalizations by category and function		
Can recall verbal events in sequence (he said, then she said etc.)		
Can focus on conversation in the presence of other stimuli (e.g. TV)		
Can go beyond stereotypic utterances		
Stays on topic in a conversation		
Demonstrates selective attention (knows what is important to pay attention to)		

Suggested Accommodations:



- Do not use figures of speech, euphemisms or sarcasm
- Use non-verbal cues to assist when giving instructions
- Avoid "why questions
- Introduce new skills within the environment in which it will be used
- Give instructions and directions one step at a time while checking for understanding along the way
- Have the individual repeat instructions or directions in own words
- Provide photocopies or audio tapes of important information
- Try to match your communication level to the FAS individual's level
- Introduce language expanding techniques very gradually, adding one small concept or vocabulary item at a time
- Use multi-sensory strategies (visual, auditory, tactile, kinesthetic) to introduce new language concepts in a variety of settings
- Use alternative demonstrations of knowledge such as videotaping, audio recording, computer graphics applications
- Encourage the use of electronic spell checkers, tape recorders and word processing
- Be patient allowing the individual to talk about own experiences to facilitate organization of thoughts



Handout #4 General Workplace Accommodations

If an individual seems to have difficulty in any of the areas on the checklists in handouts 1,2, and 3, those difficulties are likely to present themselves in the workplace, causing frustration for the individual and the employer. Below are a few suggested accommodations for the FAS/FAE individual in the work place. I am going to call our hypothetical individual "Jak".

Jak might find it helpful to select and use several of the following strategies in his work site.

These strategies can improve success on the job, help manage day-to- day work situations, strengthen relationships with co-workers and supervisors and help maintain employment.

If Jak is unemployed or would like to change jobs, spend time talking about the jobs Jak would like to have. Visit work sites that employ workers with these job titles. Talk to the employers, supervisors, and workers about the job skills and attitudes needed. Then, review the following strategies and decide which ones will be most helpful for Jak to be successful as a worker in the different job situations.

Make a list of strategies that can be helpful on the job.

Select strategies based on the strengths and weaknesses suggested by the checklists.

Examples would include carrying a tape recorder to record instructions or directions, using a pocket-size colored overlay to make any reading material easier to read (in the case of scotopic sensitivity difficulty), and being able to ask for help when needed.

Write down personal strengths and how they could apply to job situations. Include skills, attitudes and assets as they relate to his specific jobs. For example, office work strengths might include "I like people," I like to be helpful," and "I am on time." Food service strengths could include "I am clean and neat," "I know how to measure and do basic math," and "I am helpful." Shipping strengths could be "I am careful and check myself," "I know about safety," "I can lift," and "I know how to drive."

Practice asking questions.

Jak can use questioning to clarify how to do something, show interest in a coworker, or become one of the team. Jak should know the difference between questions that are friendly and casual and questions that would be considered too personal to ask co-workers.

Discuss when and where profanity or slang should not be used.

Different work situations require different types of language and work habits. don't assume that these differences are easy to figure out. Discuss these difference with Jak and talk about what types of language are OK or not OK and when, where, and with whom.



Practice giving and receiving compliments.

This aspect of communication is known as pragmatics and is the most common area of difficulty for FAS individuals. It is easy to confuse language "fluency" with the ability to use language in a socially appropriate way.

Co-workers can be a source of support, and they need support in return. Compliments give co-workers feedback on their performance. Accepting compliments is often difficult. Discuss works to use when accepting positive feedback.

Demonstrate how body language and facial expressions send messages.

Jak can learn the messages that different expressions or body movements send and when each is appropriate or inappropriate. Have Jak practice body language and facial expressions with friends.

Devise ways to track time.

Use a watch with a built in timer and alarm to help Jak monitor time on the job, serve as a reminder when to start or return from coffee breaks, and signal other important times (e.g. meetings). It might also be helpful to carry a small pad of paper with notes regarding times to start and end the workday, breaks, etc. Practice "clocking in", make plans on how to arrive on time just as workers do on the job.

Use a calculator for all arithmetic processes.

Carrying a small calculator can reduce the stress of having to mentally figure out number or money problems on the job or in daily life situations.

Make a list of ways to manage stress on the job.

Talk with Jak about situations that might occur on the job, list the ways to handle those situations and then do some role playing to practice the techniques. Also discuss ways to avoid stress, such as getting plenty of sleep, avoiding alcohol or drugs before going to work, or taking a hot shower before going to work.

Hold regular "in-service" training sessions.

Topics might include answering business phones and taking messages, filling in forms, providing quality customer service, or on-the-job safety. Teach Jak how to apply his favorite learning strategies to an on-the-job training situation to prepare him to help his supervisor on the job.



tae		m (TB5)—	
tes			



Behavior is Communication

Presenter

Paula Cook, Special Education Teacher

Lord Nelson School 820 McPhillips Street Winnipeg, Manitoba, Canada, R2X 2J7 Tele: (204) 586-1908 direct line

Fax: (204) 582-6558

Abstract

Many children and youth with Fetal Alcohol Spectrum Disorders (FASD) are bilingual – they speak with language and behavior. Much communication occurs through behavior. Every person, regardless of ability, gender, ethnicity, and so on, communicates through their behavior. We can tell when our spouses, children or bosses are in an unpleasant mood, and others can tell when we are in an unpleasant mood. But for children and youth with FASD, their behavior often becomes an overriding issue. Children and youth with FASD speak with their behavior. Inflaming the issue of inappropriate displays of behavior are poor social skills, difficulties with short-term memory, poor language skills, impulsivity and hyperactivity. This session will be fun and interactive. We will talk about how behavior, which is communication, is often misinterpreted. Blending and balancing behaviorism/behavior modification with the FASD model of behavior support will be discussed. Various strategies and methods of teaching appropriate behavior, language, matching emotions with feelings, and other coping skills will be highlighted.

Notes		



Paradigm Shifts and FAS/E

As our understanding of the meaning of 'organic brain differences' is integrated into everyday life, parents, caregivers and community members undergo a personal and professional paradigm shift in how they understand and feel about children who have been prenatally exposed to alcohol, drugs, and/or inhalants. This shift includes moving:

From Seeing the Child As:

To **Understanding** the Child As:

Won't Bad Lazy Lies

Doesn't Try Mean

Does Not Care, Shut Down

Refuses to Sit Still Fussy, Demanding

Resisting

Trying to Make Me Mad Trying to Get Attention

Acting Younger

Thief Doesn't Try Inappropriate

Not Trying to Get the Obvious

Can't

Frustrated, Defeated and Challenged

Tries Hard

Confabulate – Fills In Exhausted or Cannot Start Defensive, Hurt, Abused Cannot Show Feelings Over-Stimulated Over-Sensitive

Doesn't Get It Can't Remember

Needing Contact and Support

Being Younger

Does Not Understand Ownership

Tired of Always Failing

May Not Understand Proprieties Needing Many Re-Teachings

Preliminary findings from a University of Wisconsin study indicate that professionals shift from a paradigm of:

A Personal Shift from:

Hopelessness

Fear

Chaos and Confusion

Anger

Power Struggles Frustration Exhaustion

No Good Outcomes

Isolation

To Feelings of:

Hopefulness Understanding

Organization and Meaningfulness Reframing Perceptions and Defusing Working With, Rather Than At Trying Differently, Not Harder Reenergized / New Options to Try Recognizing / Supporting Strengths

Networking / Collaborating

Professional Practices Shift,

From:

Traditional

Applying Consequences Traditional Interventions

Changing People

To:

Recognizing Brain Differences Preventing Problems Expanding Professional Options and Developing Effective Strategies

Changing Environments





From Diane B Malbin



Resiliency Factors for Children

(Kathy Jones. Winnipeg, Manitoba)

SOCIALLY COMPETENT

Resilient Children

- -understands social cues
- -good social skills
- -uses higher order thinking

Children with FAS/E

- -tend not to see social cues
- -struggle in social situations
- -need to be taught & retaught social skills

GOOD PROBLEM SOLVING SKILLS

Resilient Children

- -good problem solvers
- -able to deal with stress
- -uses higher order thinking

Children with FAS/E

- -difficulty making choices
- -poor problem solving skills
- -struggles in stressful situations

ABILITY TO TAKE INITIATIVE

Resilient Children

- -goal focused/self motivated
- -able to initiate & sustain attention/work
- -able to control impulses

Children with FAS/E

- -difficulty maintaining focus/
- -impulsive and hyperactive
- -struggle in social situations

FLEXIBLE

Resilient Children

- -able to make choices
- -able to handle changes and transitions

Children with FAS/E

- -tend to have rigid outlooks
- -may have mental health difficulties
- -lower IQ

Paula Cook (204) 475-2601 or (204) 586-1908



Action Plan

	Name	Name	Name	Name
Continue				
Start				
Do More				
Do Less				
STOP Stop				
Signatures				

copywrite Paula Cook (204) 475-2601 or (204) 586-1908



Noisy Diagnoses: Clarity Problems Using the DSM as a tuner in FASD

Presenter

Randy Moss, Ph.D.

Copper River Native Association P O Box 4194 Palmer, Alaska 99645 (907) 745-6518

email: iccmoss@mtaonline.net

Abstract

Individuals with FASD commonly have many AXIS I Diagnostic Statistical Manual (DSM) diagnoses identified by single symptoms shuffled into clusters. This presentation will explore the limitations of the conventional DSM system with its hierarchical five axes shuffling method in describing and diagnosing FASD. The complex interplay of behaviors, symptoms and labeling syndromes will be examined using a heuristic approach, *Emergent Contextual Analysis* (ECA), which was developed by the presenter. Extra-boundary symptoms common to many DSM IV categories and FASD will be explored using ECA. This approach allows for specific behavior meanings to inform the emergent clinical picture, instead of definitional clustering.

Notes			





Change? Me?

 "We would rather be Ruined than Changed We would rather Die in our dread than Climb the cross of the moment

And let our Illusions die"



WH Auden

Fetal Alcohol Spectrum Disorders 'measures commonly used'

- Dysmorphological Measures
- Cognitive/Information Processing
- Emotional Regulation
- Developmental Stage
- Social Skills
- Language Use



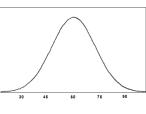
Spectrum: Whats it mean

 "... A range of values of a quantity or set of related quantities

The American Heritage Dictionary

"Some of most and most of some"

Street Speak



Face to Face

- FASD is most recognized by the outward reflection of exposure: the face. By dysmorphological means the FASD question is no longer begged. Sadly, without it, the current diagnosis is more static than song.
- "The problem with a face-based diagnosis is that it isn't the face that needs the services".

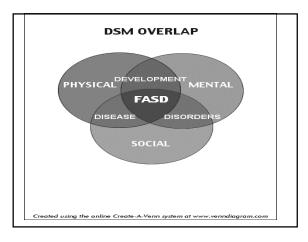
Ann Streissguth

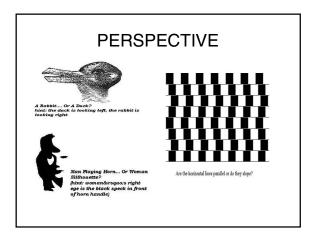
DSM Diagnostic Interference



FASD does not have a simple or repetitive pattern of challenges, deficits or diagnostic categories. The presentation of many overlapping syndromes can confuse the client and practitioner.







Cognitive/Information Processing

- Axis I
 - Learning Disorders
 - Attention Deficits
 - Affective Disorders
- Axis II--- Mental Retardation
- Axis III---Traumatic Brain Injury, Seizures, Degenerative Disorders
- Axis IV---Childhood Abuse, Culture



Emotional/Conduct Regulation

- Axis I
 - Affective Disorders

Sleep Disorders Psychotic Disorders

- Impulse DisordersAutistic Spectrum
- Substance Related Disorders
- Axis II---Personality Disorders, Mental Retardation
- Axis III---TBI, Seizures, Hormonal Dysregulation, Degenerative Disorders
- Axis IV--- Abuse, Poor Primary Environment

Developmental Disorder

- Axis I
 - Autistic Spectrum
 - Attachment Disorder
 - Conduct Disorder
 - Learning Disorders
 - Motor Coordination Disorders
- Axis II--- Mental Retardation, Personality Disorders
- Axis III--- Disintegrative Disorders, Hormonal Dysregulation,
- Axis IV---Poor Primary Environment, Abuse

Social/Relational Disorders

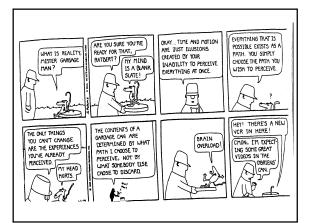
- Axis I
 - Communication Disorders Psychotic Disorders
 - Attachment Disorders Conduct Disorders
 - Autistic Spectrum Disorder
 - Attention Disorders
 - Other focuses of clinical treatment
- Axis II---Mental Retardation, Personality Disorder Features
- · Axis III--- TBI, Seizure
- Axis IV--- Abuse, Poor Primary Environment



Language Disorders

- Axis I

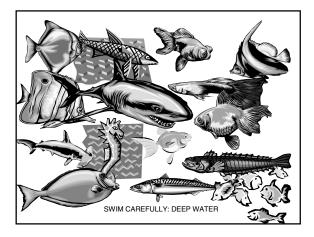
 - Autistic Spectrum Disorders Conduct Disorders
 - Attachment Disorders
- Axis II---Cluster A Personality Disorders, Mental Retardation
- Axis III--- TBI, Degenerative Disease, Stroke, Cancer, Heart Failure
- Axis IV--- Neglect, poor schooling, poor primary environment



Netting or Clustering

> Symptoms are like fish, many different kinds swim together. The clinician casts the net and gathers in the fish. We sort and keep those that we are familiar with, paid to keep or are of the most obvious. Even how we deploy the net; where, when and the mesh size, is not wholly dependent on the fish but upon the fisher.





De-Constructing the DSM



- History
- Foundational Philosophies
- Definitions
- Limitations

Tyranny of Labels

- Uni-Dimensional Descriptions
- Weakness/Deficit Orientated
- Internalized Organizing Principle/Narrative
- External Representational Schema



Shallow Categories

- Artificial Definitional Taxonomy
- Powerful Elitism
- Perspectival Non-Exclusivity
- Ungrounded Ontology and Nosology

DSM De-Constructed

- History Toward Monolithic Abnormality
- Categorical Creep
- Codification of Fallacy of Interiorization
- Content Criteria vs Contextual Analysis

DSM History

- 1952 --- DSM... Attempt to generate common language about "reactions"...100 pages. Assumption 1:10 "Reactions"
- 1968---DSM II...Migration from "reactions" to "Mental Disorders"
- 1980---DSM III... Criteria based schema with introduction of multi-axial classification "Mental Disorders and Syndromes" 400 pages



DSM History cont

- 1987---DSM IIIR... Clarifications and some "tweekings" of axes system. Included Organic Based Disorders and other etiological explanations
- 1994---DSM IV... Dropping of Organic Mental Syndrome due to complete "biologizing" of Mental Health. 900 pages Assumption 1:3 "mental Illness"

F	200m	without	a View
Г	コレルカロロ	VVIIIICALAI	a view

• The convention of the DSM and subsequently, public discourse, gives privilege to the first descriptor (Dx) as the most important, most inclusive, and etiologically accurate. This hierarchical presentation in DSM structure does irreparable damage to the FASD client and stagnates social and environmental freedoms and creativity to accommodate a whole potentiality (person).

DSM Static

Why the song is not clear

 "Over 90% of the patients with FAS/FAE had mental problems. It is wiser to begin treatment by attempting to look at areas of stress in the environment that to plunge into the use of medication"

Streissguth and O'Malley, 1997



Emergent Contextual Analysis

Presenting problems unfold along the course of relationship and time helping to define the source and challenges of the underlying issue.
 What is initially seen is not the whole or true story



Emergence

 The concept of Emergence comes from a field of physics. In FASD, time, space, spin and meaning all must EMERGE before the extent and impact of each life challenge can be understood



Contextual Analysis







Context

- Cultural Meaning
- Personal Meaning
- Objective Measure or r leaning
- Time and Timing
- Triggers
- Results
- Physical Environment

FASD as Disability

- DSM does not interpret Disability in the functional sense. Disability in the sense of this presentation means "the inability, without environmental support and adjustment along with an external source of information processing (brain), to reach individual potential, happiness and inclusion."
- The FASD individuals have multiple disabilities that need such adjustments and supports.

DSM as Chord Measure

 DSM nosology and structure don't allow for a clear hearing of the full song. What is important is that DSM can help identify certain notes, special chords and even important phrases of the song. To hear though, one must allow the full playing to understand the artist, the rhythm and verse. ONLY then can we offer focused support and orchestration.

4.	
	FAS Summit 2002

Noisy Diagnoses (F02)————————————————————————————————————
Notes



FAS is Not for Children Only: Strategies for Adolescents and Adults with FAS/E

Presenter

Dan Dubovsky, MSW

FAS Specialist CSAP FAS Center for Excellence 1700 Research Blvd. Suite 400 Rockville, MD 20850 301-294-5479

fax: 301-294-5401

e-mail: ddubovsky@northropgrumman.com

Abstract

The sequelae of FAS and FAE do not magically vanish at the age of 18 or 21. The difficulties that persons with FAS/FAE experience continue into adulthood. However, since there has not been much systematic research on intervention strategies for adolescents and adults with FAS/FAE, many are caught in systems that are ill equipped to understand their difficulties and needs and provide optimal treatment. This session will examine some of the difficulties that adolescents and adults with FAS/FAE often experience in settings such as school, job, social situations and corrections. We will, with participants' input, discuss intervention strategies that families and professionals can advocate for and utilize in each of these settings.

Learning Objectives

By the end of this presentation, participants will be able to:

- 1. describe difficulties that individuals with FAS/E experience in various settings;
- 2. discuss reasons that adolescents and adults with FAS/E have difficulties in these settings;
- 3. examine strategies for addressing these difficulties;
- 4. identify difficulties in their own situation that they might address differently.

Notes			



otes		



BRAIN GYM®: Self Care for FASD Individuals, Family, Friends and Care Providers

Presenter

Lisa Farber

Certified Brain Gym Instructor Learning Dynamics 18560 Rouse Circle Eagle River, AK 99577 (907) 696-0901 email: learningdynamics@alaska.net

Abstract

Brain Gym® is a dynamic tool you can use right away, at home or at work to release stress. These movements simply reconnect the brain hemispheres, allowing a person to move from being "ineffective" to "effective." To be more energetic, think more clearly and make decisions more easily. Learn how to easily decrease stress, be more relaxed and effective by using simple and fun activities.

Notes			



PACE (POSITIVE, ACTIVE, CLEAR & ENERGETIC)

WATER

Increase water in times of stress.

- creates efficient electrical & chemical action in the brain
- alleviates mental fatigue
- releases stress
- enhances communication & social skills

BRAIN BUTTONS

Find two indentations directly under the collarbone, gently massage. Place other hand over naval. Hold 20-30 seconds, switch hands.

- activates left/right brain hemispheres
- increases oxygen to the brain
- alleviates visual stress

CROSS CRAWL

Can be done sitting or standing. Place right hand on left knee, then left hand on right knee. Repeat 20-30 times, don't rush!

- stimulates right/left brain hemispheres
- improves whole body coordination
- increases ability to cross all midlines (auditory, visual, kinesthetic and tactile)

HOOK UPS

Extend arms out, place backs of hands together, thumbs down; cross one hand over the other, pull into chest. Cross ankles and place tongue on the roof of the mouth.

- increases respiration
- improves focus
- releases stress

H₂O







Source: Brain Gym Handbook by Dr. Paul E. Dennison & Gail Dennison

Learning Dynamics (907) 696-0900

learningdynamics@alaska.net



BRAIN GYM®: A TOOL FOR FAMILIES, FRIENDS AND CARE PROVIDERS

Brain Gym® is a dynamic and fun way to improve all learning skills and behavior for students of any age. Simple, directed movements enhance brain connections to make learning more automatic, moving the learner from the "trying" mode in to a more relaxed state. Developed by Dr. Paul E. Dennison, Brain Gym was created based on an understanding of the interdependence of physical development, language acquisition and academic achievement.

LAZY 8's

Draw a number 8 on its side; start in the middle, directly on the midline. Go up first, keeping head still and using eyes to track. Start small; if easy, then get bigger. If difficult, try a small plus sign instead.



- encourages eye teaming
- enhances ability to cross visual midline
- increases peripheral vision

THINKING CAP

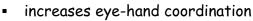
Gently unroll edges of both ears from top to bottom, 4-5 times (until they get hot).

- increases ability to focus
- improves memory
- stimulates ears for "switched-on" hearing



DOUBLE DOODLE

Picture an imaginary line up and down the midline, place hands (with or without pens) in the air or on a board & move them in/out and up/down, making mirror images on either side of the line. Two people can do this activity facing each other. Create any shapes you want.



- improves right/left awareness
- enhances ability to encode/decode



Source: Brain Gym® Teacher's Edition by Dr. Paul E. Dennison and Gail E. Dennison

Learning Dynamics (907) 696-0900

learningdynamics@alaska.net



Brain Gym: A Tool for Families, Friends and Care Providers (FA2)-

Resource Material

Awakening The Child Heart-Handbook for Global Parenting by Dr. Carla Hannaford The importance of play, sound, music and the heart for parenting and life-long joy and learning. Many "how-to's" that can be used immediately!

Brain Gym® and *Brain Gym*® Teacher's Edition by Dr. Paul E. Dennison & Gail E. Dennison These books are packed full of information on basic Brain Gym activities, how to do the movements, the academic and behavioral benefits and variations on each movement.

Brain Gym® Three Day Rotation by Ann RaNae Meders

An easy way to make Brain Gym® an important part of your students' daily routine.

The Brain Train-How To Keep Our Brain Healthy & Wise by Frances Meiser

Discover what foods are good for the brain! Book for all ages.

The Dominance Factor by Dr. Carla Hannaford

This book examines the linkages between the side of the body we favor for seeing, hearing, touching and how knowing this information can benefit the way we learn.

Edu-K for Kids by Dr. Paul E. Dennison & Gail E. Dennison

Prepared for teachers and parents, this book is easily understood and includes step-bystep procedures.

I Am the Child: Using Brain Gym With Children Who Have Special Needs by Cecilia K. Freeman with Gail E. Dennison

An exciting and innovative work that will bring untold riches to children and adults with special needs, as well as those teachers, parents and therapists that work with them.

The Learning Gym by Erich Ballinger

Experience this delightfully illustrated book that has captured the hearts of Europeans since its publication in 1992.

Personalized Whole Brain Integration by Dr. Paul E. Dennison and Gail E. Dennison This book will enable you to "switch on" to a higher level of performance and a deeper level of appreciation for your own uniqueness through an understanding of your brain organization profile. Maximize your potential through simple, directed movements.

Smart Moves by Dr. Carla Hannaford

This easy to understand book explores the nature of intelligence, and how the body/mind processes sensation, emotion and thought. It emphasizes the power of Brain Gym to enhance learning and reduce stress.

Switching On by Dr. Paul E. Dennison

Easy to master techniques to help students integrate right and left brain functions.

"Education in Motion" (videotape) by Dr. Carla Hannaford, Cherokee Shaner, Sandra Zachary and Linda Grinde

A 22 minute introduction to Brain Gym.

"New Paradigm in Reading Instruction" (videotape)

A clear, dynamic and exciting message from the founders of the Foundation for Educational Kinesiology – that education must examine itself and make a paradigm shift and how Brain Gym can play a role in moving into more effective learning.

www.braingym.org

Risk Management Teams, Restorative Justice and Intercommunication with the FASD Community

Presenter

Keith Thayer, Probation Officer III

State of Alaska, Department of Corrections Division of Community Corrections 4500 Diplomacy Drive, Suite 219 Anchorage, AK 99508 (907) 269-7391 email: keith_Thayer@correct.state.ak.us

Abstract

This presentation will give an overview of the Division of Community Corrections (DCC) and its concentration on restorative justice. Completion of this training will allow attendees to participate as members of DCC "risk management teams (RMTs)." Specifically, DCC plans to incorporate this form of extended community supervision and service to better address higher risk and/or higher needs offenders to include offenders with FASD. This presentation will also help people better navigate the DCC system and foster intercommunication with the FASD community and DCC."

Notes		



Department of Corrections
Risk Management Team Training
FAS Summit 2002
Anchorage, Alaska
November 22nd

Risk Management Teams
Division of Community Corrections

Keith Thayer, Probation/Parole Officer
Manager Village Public Safety Officer Program
Tim Astle, Probation/Parole Officer
District Supervisor- Anchorage Adult Probation & Parole

Mission Statements

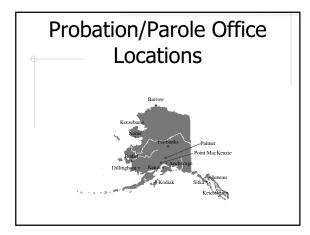
The Department of Corrections

In partnership with the citizens of Alaska, protect the public from recidivistic crime by using best correctional practices to provide a continuum of appropriate, humane, safe, and cost-effective confinement, supervision, and rehabilitation services to people remanded to the custody of the Department of Corrections.

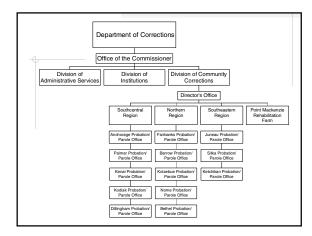
The Department will carry out its responsibility while respecting the rights of victims and recognizing the dignity inherent in all human beings

The Division of Community Corrections

To provide for the reintegration and supervision of offenders in the community; pre-sentence investigation and oversight of community programs.







Probation and Parole

Probation

Supervision for adult felony offenders imposed by the judge as an alternative sanction to jail/prison or following release from incarceration

Discretionary Parole

Conditional release by the Alaska Board of Parole of a prisoner serving a sentence exceeding 180 days; to serve the remainder of their time on parole supervision if they agree to adhere to the conditions of release chosen by the Board.

Mandatory Parole

Conditional release of a prisoner serving a term of two years or more before the expiration of the term for the remainder of their statutory good time whether he/she agrees to the parole conditions or not.

Paradigms of Justice Retributive Justice Restorative

Crime is understood as a

- violation of the State
- Focus on the past and establishing blame
- Actions directed from State to offender
 - -Victim Ignored
 - -Offender Passive

Restorative Justice

- Crime is understood as a violation of people and personal relationships
- Focus on the future and problem-solving
- ♦ Victim and offender's roles recognized in both problem and solution
 - -Victim rights recognized
 - -Offender encouraged to take responsibility



Paradigms of Justice

Retributive Justice

- Community on the sideline and represented abstractly by state
- Imposition of pain to punish and deter
- Offender accountability defined as taking punishment
- Encouragement of individualism
- Offense understood only in legal terms

Restorative Justice

- Community as a facilitator in the restorative process
- Restitution as a means of restoring both parties
- Offender accountability defined as understanding the impact of actions and repair of social injury
- Encouragement of mutuality
- Offense understood in the wider moral, social, economic and political context

Establish Risk Management Teams

- Enhances Supervision of felony offenders through community contacts/supports
- Educates the community about public safety issues and affords the community the opportunity to be part of the solution
- Promotes pro-social norms such as offender accountability, taking responsibility, and honesty
- Participates in the promotion of protection of the public and reformation of the offender in the present and into the future.

Our Mission

To provide a RMT program to felony offenders who are under the authority of DOC, using an integrated and coordinated risk management model.

FAS Summit 2002	
2002	100

Team Goals

- ♦ To reduce the offenders risk of re-offense
- To enlist the participation of formal and informal community resources in the management of risks posed by the offender

Objectives of RMT

- Identify risk factors specific to the offender that led to offending
- To assist community resources and the offender in identifying strategies to reduce the risk of re-offending
- To develop strategies for monitoring behaviors/situations that may contribute to offending
- To assist the offender in identifying counseling alternatives to address risk factors that led to the offending

 To assist the offender in identifying and developing a support/risk management network outside the RMT
- management network outside the RMT
 To provide community education on the topic of criminal offending
 (sexual offending, DWI, etc.)
 To assist victims (child, non-offending partner, other family members)
 in exploring and identifying counseling alternatives
 Assist the community in identifying and monitoring known high risk
 offenders

Benefits of RMT

- $\ensuremath{\spadesuit}$ Improves communication among service providers and community members
- Allows faster responses to victims
- Promotes the exchange of ideas
- Increases the understanding of individual needs when monitoring the offender
- Increases monitoring/supervision of the offender
- Decreases offender manipulation of information that often occurs with offenders
- Minimizes burnout of team members
- Decreases fragmentation of service providers that work with the offender and family



Who makes up the RMT Probation/Parole Officers Family and Children Services Lay person/counselors Professional counselors in offender's life Alcohol/Drug counselors Iders Clergy Volunteers Fingloyer Partner of Offender Child Advocates Tribal members, wellness workers Victim Service Workers Grender's personal supports Mental Health Workers Alcohol/Drug counselors

Likely candidates for **RMT**

- Not in denial of the underlying conviction
- Understand offense dynamics, cycles
- Agree not to keep secrets
- Are willing to communicate with all members of the team
- Are willing to be contacted at home or work

Potential Obstacles

- Competitive attitude, defensiveness
- Lack of personal and organizational support
- Lack of understanding
- Failure of any/all parties to communicate
- Hero-stance Victim cycle
- Lack of role clarity
- Lack of diversity
- Inadequate written policy, procedure, and team rules
- Rigid adherence to rules
- Failure to follow-up and evaluate

-		
-		
-		
-		
•		
•		
•		
-		



RMT... Getting off the ground Comprised of formal community resources Comprised of informal community resources

- Offender is convicted
 Probation/Parole Officer can recommend a condition of release for participation in a RMT
- Case Plan is established addressing residence, employment, and treatment needs; Level of Service Inventory (LSI-R)
 Potential RMT members are identified and releases of information are
- initiated and signed
- Contacts are made with potential RMT members and an orientation meeting is set up with the team
- The team establishes the mission, objectives, and goals in collaboration with the offender
- The team becomes instrumental in assisting in the offenders reformation while also furthering the call to public safety

Thank you for your time and attention. Should you have any questions or require any assistance from the Department of Corrections please contact either of us:



Keith Thayer, PO III VPSO Project Manager 4500 Diplomacy Drive Anchorage, AK 99508 Phone: 269-7381

E-mail: Keith_Thayer@correct.state.ak.us

Tim Astle. POIV Tim Astle, POIV
District Supervisor
Anchorage Adult Probation & Parole
800 A Street, Suite 100
Anchorage, AK 99501
Phone: 334-2310
E-mail: Timothy_Astle@correct.state.ak.us



	ommunity (FA	(3)		
tes				



Practical Strategies for School Success for Children with FAS and Alcohol-related Conditions

Presenters

Julie Gelo

Family Advocate University of Washington FAS Diagnostic and Prevention Network 1512 175th Place S.E. Bothell, WA 98012 (425) 485-2011

email: JULIEGELO@aol.com

Tracy Jirikowic, PhC, OTR/L

Occupational Therapist University of Washington FAS Diagnostic and Prevention Network 1512 175th Place S.E. Bothell, WA 98012 (206) 285-2145

Abstract

Children with FAS and alcohol-related diagnoses demonstrate many strengths and challenges in the school setting. This workshop will explore selected behavioral and academic problems in the preschool, elementary school and high school settings. Intervention ideas that focus on proactive planning strategies, environmental modifications, and accommodations to improve success in the classroom will also be presented. The content of this workshop will include background information from research literature, case presentations and examples, as well as several practical hands-on intervention strategies.

Notes		



Practical Strategies for School Success for Children with FAS and Alcohol-related Conditions

Julie Gelo and
Tracy Jirikowic, OTR/L
University of Washington
FAS Diagnostic and Prevention Network
FAS Summit November 21 and 2002

Today's Objectives

- Discuss advocacy strategies and creative ways to support learning and healthy development in the school setting.
- Discuss intervention strategies and classroom accommodations for preschool through high school.
- Discuss ways to plan and facilitate successful transitions.

Strategies & Suggestions Based on the Following:

- Reported/observed behavioral challenges that interfere with learning and academic instruction
- Reframing and understanding these behaviors is crucial to support success in school
- Anticipating and accommodating needs can minimize/prevent challenging behaviors

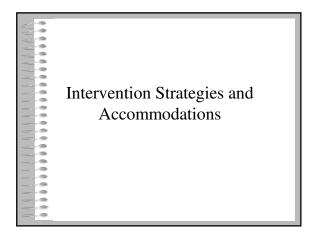


Preparing for the School Year • Planning ahead • Prioritizing goals • Advocacy strategies

A Framework for Understanding Difficult Behaviors • NEEDS • BEHAVIOR • RESPONSE

Understanding Challenging Behaviors					
• Evaluate the demand					
- Consider age/developmental level					
• Observe the environment					
- Sensory, safety, supervision					
Recognize signs of stress & overstimulation					
- How is child coping?					
• Communication					





Getting Through the School Day: Preschool • Getting ready for school - Evening and morning routines - Picture schedules • Riding the bus - Supervision - Communicating with the team & the bus driver

Getting Through the School Day: Preschool Transitions and Change - Preparing for transitions Calming Down - Quiet spaces - Knowing what triggers the behavior - Intervening early



Getting through the School Day: Elementary School Getting ready for school - Schedules and routines Riding the bus - Supervision plan - Seat assignments Paying attention - Seating arrangement (desk size, location) - Minimizing distractions - Movement breaks

1/1////	Getting through the School Day: Elementary School					
	Recess/Lunch - Adequate supervision - Structured activity choices - Impact of the environment Writing - Technology/adaptations - Alternatives to writing					
0000000	Transitions and Change - Substitute teachers - Schedule changes Organization					

Getting through the School Day: Elementary School Calming down Quiet spaces After-school activities Safety and supervision Tasks that match the child's developmental level & strengths Homework Time limits Communication between parent and teacher



Getting through the School Day: Middle and High School Organization - Visuals, extra instructions Pre-vocational activities/life skills After-school activities Homework - Time limits - Communication - Examine schedule

~						
~	Getting through the School Day:					
	•					
-	Middle and High School					
	Getting ready for school					
	Getting ready for senoor					
	 Routines and schedules 					
	C					
	 Supervision according to developmental level 					



The Effects of Fetal Alcohol Spectrum Disorders on the Eye and Visual System

Presenter

Charles Jaworski, OD, FAAO, USPHS

Director of Eye Care Norton Sound Health Corporation P. O. Box 966 Nome, AK 99762 (907) 443-2326

email: chuck@nova.edu

Abstract

Notes

This presentation will give an overview of the eye and vision disorders found in patients who suffer from Fetal Alcohol Spectrum Disorders. Because of the high frequency of ocular disorders found in these patients (some studies show up to 90%) it will be recommended that a complete ocular exam be preformed prior to the diagnosis of this disease. The visual, perceptual, and developmental consequences of the visual problems will be discussed. In addition, treatment and intervention strategies will be presented.

This session was previously scheduled as "Strategies for Working with Individuals Experiencing FASD and Vision/Hearing Impairments" Handouts begin on page 189					



on the Eye and \ Notes	visual System	(FA5)		



Creating Change: Community Outreach and Networking

Presenters

Margaret Parsons-Williams, FAS Coordinator Gloria Stuart Pam Collman

Frontier Community Services 43335 K-Beach Street Road, Suite 36 Soldotna, AK 99669 (907) 262-6331

email: m_parsonswilliams@fcsonline.org

Abstract

Too many babies are born affected by prenatal exposure to alcohol. This is a problem at the community level, as well as the state, national and worldwide levels. Change must happen, but where do we start, what do we do? We start by linking larger communities to smaller ones, and sharing ideas, resources and inspiring each other to generate new ideas and innovations. This workshop will explore ideas and generate resources on how to tackle FASD prevention and intervention. Members of the Kenai Peninsula Diagnostic Team will share the efforts they have begun to further the goal of bringing about change. Participants will be asked to share their activities, experiences and ideas to help further this goal.

Notes			



CREATING CHANGE: COMMUNITY OUTREACH AND NETWORK ACTIVITIES ON THE KENAI PENINSULA

- I. Large workshops with national/international FAS Presenters
 - A. FASCETS-Sunny Olsen-Kacalek
 - B. Deb Evensen
 - C. Dr. Phil Mattheis and Deb Evensen
 - D. Dr. Kieran O'Malley
- II. **Smaller trainings** by local FAS team members
 - A. Medical providers- doctors and hospital staff at Grand Rounds
 - B. School District
 - 1. District Support Staff- aides, PTs, OTs
 - 2. District Nurses
 - 3. School Assembly
 - 4. School staff meetings
 - 5. High school and middle school health class presentations
 - C. Mental Health
 - 1. Central Peninsula- Children's Program
 - 2. Kenaitze Nakenu Family Services- mental health, drug & alcohol
 - 3. Seward Seaview Community Services- mental health, DD, drug & alcohol
 - 4. Kenai Community Care Center (residential inpatient children's program)
 - D. Community Events
 - 1. Health fairs
 - 2. Children Health Fairs
 - 3. AVTEC Health Fair
 - 4. Foster Parent Trainings
 - 5. "Dine and Discuss"- educational presentation coordinated and sponsored by Central Peninsula Hospital
 - E. Adult Services
 - 1. Women's Resource Center staff
 - 2. CICADA- Drug and Alcohol providers
 - 3. Peninsula Job Center case managers and Vocational Rehab
 - F. Children's Services
 - 1. Women's Resource Center: Licensed day care providers

III. Meetings and Support Groups

- A. Children's Team: multi-agency group of providers
- B. FAS Adult Task Force: multi-agency group of providers
- C. Parent Navigator support groups
- D. After work Social for agency networking
- IV. **Co-coordinated trainings** with local and state providers
 - A. Speech Pathologist, Occupational Therapist and Physical Therapist "Sensory Integration"
 - B. Parent Navigators- Cheri Scott and Mary Lou Canney
 - C. Disability Law Center-Teresa Holt



V. Publicity

- A. Newspaper
 - 1. Article with interview of national presenter
 - 2. Article about family life with FAS child around FAS International FAS Awareness Day (in the 3 local newspapers)
 - 3. Meeting notices (Around the Town, Neighbors)
- B. Radio announcements (PSA and paid spots)
- C. Program Brochure distributed widely in the community by hand
- D. Flyers mailed to parents, faxed and e-mailed to service agencies, and posted at local businesses
- E. FAS International Awareness Day- cards and pins made and distributed by local service groups, churches, and families to schools, agencies, government offices, hospitals, retail businesses, and families
- F. Workshop Certificates given to participants
- G. Poster contest





Yoga and Massage for the Special Child

Presenter

Michéle Aitken, NCLMT, Speaker and Educator

8341 Sue Street Anchorage, Alaska 99502 (907) 529-6921 email: aitken@gci.net

Abstract

This workshop is an introduction to Yoga and Message and how this particular modality helps to support body function and strength. The gift of focus through breathing, stretching and relaxation are some of the benefits of these methods. The results of a pilot program through the Alaska Waiver program will be discussed with an emphasis on the improvements seen on neurological, physical, and mental levels. If time allows a demonstration of the techniques involved will be given.

Outline

- I. Introduction- About myself
- II. History of Yoga for the Special Child-founder Sonia Sumar
- III. The Magic of Yoga- why is it special?
- IV. Benefits of Yoga- How it can help FAS.
- V. Massage, breathing, and meditation.
- VI. Specific personalized program for each child's needs
- VII. Summary

Notes		



Yoga and Massage for the Special Child (FA7)————————————————————————————————————
Notes



The Use of Medication for Treatment of Mental Health Difficulties: An Overview

Presenter

Dan Dubovsky, MSW

FAS Specialist CSAP FAS Center for Excellence 1700 Research Blvd. Suite 400 Rockville, MD 20850 301-294-5479

fax: 301-294-5401

e-mail: ddubovsky@northropgrumman.com

Abstract

Many individuals with FAS/E have behaviors that interfere with their ability to participate positively in a variety of settings. In many instances, these individuals have co-occurring mental health disorders that may benefit from treatment with medication as part (never the only piece) of the treatment plan. This workshop will present an overview of how and why we believe medications work to help improve the symptoms of mental health disorders. We will discuss why individuals with FAS/E might have these disorders and what part medication plays in their treatment. We will also talk about medication use to address behaviors and what should be the goal of using medication which is to help the individual control his/her thoughts and actions. The workshop will address questions that individuals taking medication, families, and providers should be asking those who are prescribing medication.

Learning Objectives

By the end of this presentation, participants will be able to:

- 1. identify medications that are used to treat psychiatric disorders;
- 2. examine mental health disorders that may co-occur with FAS/E;
- 3. discuss the role that medication can play in treatment;
- 4. list questions that should be asked of prescribing physicians.

Notes			





Providing Treatment Services to Individuals with FASD

Presenter

Candace Shelton, M.S., CSAC, CCS

Clinical Director
Behavioral Health
Native American Connections, Inc.
6965 N. Camio Verde
Tucson, Arizona 85743
(520) 579-3425
email: canshelton@aol.com

Abstract

This workshop will explore the traditional methods for substance abuse treatment and considerations that need to be made for those individuals who themselves are impacted by neurological damage resulting from prenatal exposure to alcohol. Knowing that alcohol abuse occurs across generations, we can assume that many individuals who themselves are alcoholic come from alcoholic families. What strategies and techniques work in providing substance abuse treatment to individuals with FASD, how do they differ from traditional models and how can we build these strategies into traditional program models.

Notes		



Providing Substa Notes	ance Abuse i	reatment t	o marvidua	us with FAS	оD (FB2)—	



The Effects of Fetal Alcohol Spectrum Disorders on the Eye and Visual System

Presenter

Charles Jaworski, OD, FAAO, USPHS

Director of Eye Care Norton Sound Health Corporation P. O. Box 966 Nome, AK 99762 (907) 443-2326

email: chuck@nova.edu

Abstract

This presentation will give an overview of the eye and vision disorders found in patients who suffer from Fetal Alcohol Spectrum Disorders. Because of the high frequency of ocular disorders found in these patients (some studies show up to 90%) it will be recommended that a complete ocular exam be preformed prior to the diagnosis of this disease. The visual, perceptual, and developmental consequences of the visual problems will be discussed. In addition, treatment and intervention strategies will be presented.

Notes	





FAS, FAE Effects on the Eye and Visual System

LCDR Charles Jaworski, OD, FAAO



The Alphabet Soup

- ♦ FAS (Fetal alcohol syndrome)
- ◆ FAE (Fetal alcohol effected)
- ◆ FASD (Fetal alcohol spectrum disorders)
- ♦ DEB (Drug effected baby)
- ♦ PDE (Poly-drug effected)



FAS and Eyes? Huh, Who Cares?





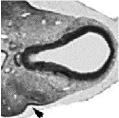


What is the primary source of disability people with FAS?

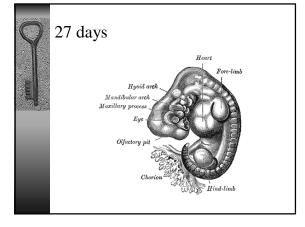
- ♦ Neurological
- ♦ Insult(s) to developing brain
- ♦ Abnormal embryology
- ♦ Smaller, abnormal structured brains
- ◆ Abnormal structure is proportional to abnormal function
- ♦ Dy/dx S OC dy/dx F



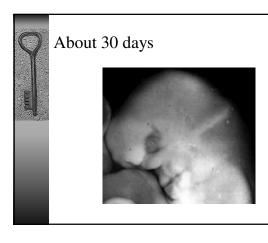
Embryologically the eye develops from the diencephalon of the brain

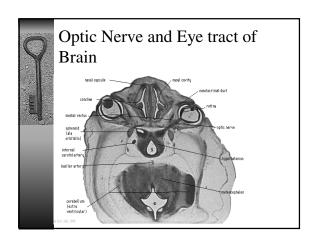


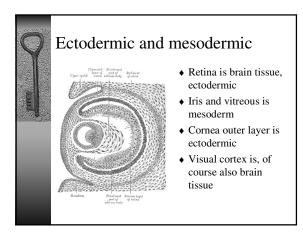
- ◆ Starts 3rd week of development
- Optic nerve is not a real nerve but a tract of the brain
- Eye only place you can see brain tissue



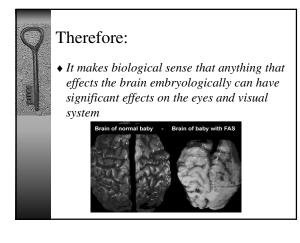


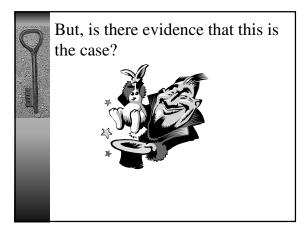


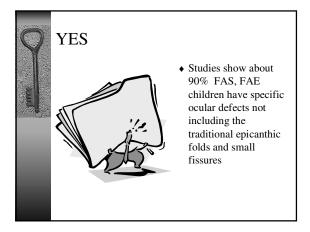
















Some specific references

- ◆ Stromland and Hellstrom, *Fetal Alcohol* syndrome, an ophthalmologic and socioeducational study. Pediatrics, June 1996
- ◆ Stromland and Pinazo, *Ophthalmic* involvement in the FAS: clinical and animal model studies, Alcohol & Alcoholism, Feb 2002



More references

- ◆ Chan, *Fetal Alcohol Syndrome*, Optometry and Vision Science, Oct 1999
- ◆ Hiratsuka and Li, *Alcohol and Eye Disease*, Journal of Studies of Alcohol, May 2001
- ◆ Hellstrom, *Optic Nerve Morphologies may* revel adverse evens during prenatal life, Survey Ophthalmology, Oct 1999



References Cont

- ◆ Hellstrom et al, Eye Size in..... Swedish children with FAS, Acta Ophal Scandinavia, Aug 1997
- ♦ Cook et al, FAS, Eye malformations in a mouse model, Archives Ophthalmology, Nov 1987
- ◆ Garber, *Corneal curvature in FAS*, Journal American Optometric Assn, Aug 1982

0.10	
FAS Summit	
FAS Summit 2002	



Summary of literature

- ♦ 90 to 100% of FAS children have specific ocular problems
- Ocular and visual abnormalities can be as specifically diagnostic for FAS as many other criterion
- ◆ An eye doctor should be part of any FAS diagnostic team



Reasons to include an eye care doctor in your FAS team

- ◆ Eye exam findings are often very specific for FAS and are invaluable if the diagnosis of FAS is in question
- ◆ Eye exams are mostly non-invasive, easy to do, and relatively in expensive (often covered by insurance)
- ♦ Many of the eye problems can be fixed or managed



To Repeat

◆ Unlike many of the other problems associated with FAS, there are effective treatments, and interventions in eye care that can significantly increase a child's functional ability





Hope in math, 'who'da thunk'

- ♦ Dy/dx S OC dy/dx F
- \bullet Dy/dx F = E(I)/Dy/dx S
- ♦ Delta S=E(I)/(dy/dx f)
- ♦ Dy/dx F is rate of functional improvement
- ullet E(I) is effectiveness of intervention (therapy)
- ♦ Delta S is amount of structural change



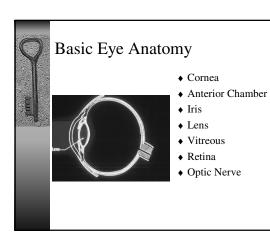


How do we test the eyes and vision of FAS people?

- ♦ Visual acuity
- Refraction
- Eye teaming
- Eye structural integrity
- Eye health
- ♦ Visual reactions
- ♦ Visual processing

					_
_					_
					_
					_
					_
					-
					-







Visual Acuity

- ◆ About 70% FAS Children have 20/70 or worse best corrected
- Multiple reasons for this problem
- ◆ Amblyopia and optic nerve hypoplasia most common





Testing Visual Acuity

- Multiple modern methods
- ♦ Charts
- ♦ OKN drums
- ♦ Preferential looking
- ♦ VER
- ♦ Functional



FAS Summit 2002



Refraction

- ♦ Nearsighted (Myopia)
- ◆ Far Sighted (Hyperopic)
- ♦ Astigmatism
- ◆ Focusing problems (accommodation)





Myopia (nearsightedness)

- ♦ Distant objects blurry
- FAS people may have severe myopia usually due to premature birth
- ◆ More commonly found in combination with astigmatism with FAS people





Hyperopic (Farsighted)

- Near objects blurry or more difficult to see
- ◆ More common with FAS children
- ◆ Often found in combination with astigmatism



FAS Summit 2002	
Summit	
2002	1



Astigmatism

- ♦ Most common refractive error in FAS
- ◆ Due to mal-shaped cornea
- ◆ If left untreated can cause Amblyopia





Accommodative (Focusing) Disorders

- Ability to look near and far in a dynamic setting
- Greatly exacerbated by uncorrected refractive errors
- ◆ Very common in children with fine motor control problems





Testing for refractive disorders

- ◆ Traditional phoropter
- ♦ Retinascope
- ◆ Auto-refractor (electronic)
- ♦ More exotic methods
- People do not need to be able to call letters or make judgments in order for the doctor to measure



FAS Summit 2002



Treating refractive disorders

- Eye Glasses
- ◆ Contact lenses
- ◆ Surgery (not recommended for FAS children)
- ◆ Treating uncorrected refractive errors can often have a remarkable effect on a person's function





Eye Teaming

- ♦ Strabismus
- ♦ Nystagmous
- Binocular disorders





Strabismus

- Eyes do not point to same area at the same time
- $ullet \ Cross-eyed, Wall-eyed \\$
- ♦ Vertical
- ♦ 40 to 50% FAS
- Results in spatial localization dysfunctions



FAS Summit	
Summit 2002	



Nystagmous

- Jerky uncontrollable eye movements
- Very indicative of neurological damage
- ♦ Can result in reduced vision



Binocular disorders



- Eyes can work together but have difficulty doing so
- ◆ Results in poor visual performance in tasks such as reading, sports, etc
- ◆ Very common in people with fine motor difficulties



Treatment for eye teaming problems



- ◆ Eye glasses (prism, occlusion etc)
- ◆ Patching
- Orthoptics
- ♦ Surgery
- ◆ Compensation
- ◆ Fringe stuff (biofeedback, meditation, etc)





Eye structural integrity

- ♦ Eye lid- face
- ♦ Cornea
- ♦ Lens
- Retina
- ♦ Optic Nerve

Eye lid and face The complete of the complete



Eye appearance of FAS Child



- Usually no treatment except if eyelid malformation causes blinking or exposure problems.
- May cause increased susceptibility to eye infections

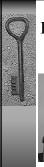
FAS Summit	
2002 2002	



Corneal



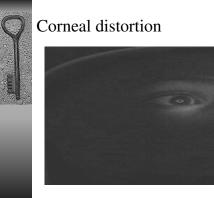
- ◆ Some studies show 100% FAS people have high corneal curvature
- ♦ Very specific for FAS
- ◆ Causes refractive errors such as astigmatism
- Resultant conditions treatable



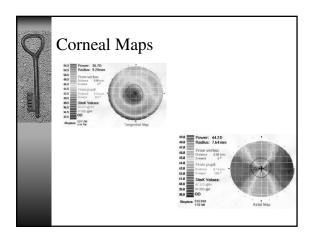
Examining the cornea

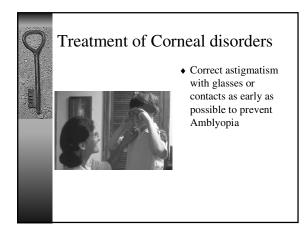


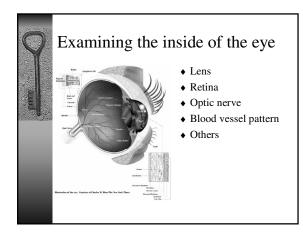
- ♦ Slit lamp
- Keratometer (electronic and analog)
- Topography
- Placedo disc



FAS Summit 2002











Ophthalmoscopes



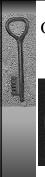
- Direct (old)
- Binocular indirect
- Slit lamp with fundus lenses
- Other weird methods



The Normal Retina (Fundus)



- ♦ Optic Nerve
- ♦ Blood Vessel Pattern
- ◆ Fovea (Central sharp vision)
- Sensory Retina (Side vision and night vision)
- Other neat stuff

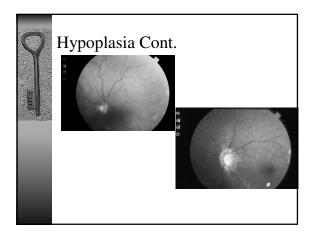


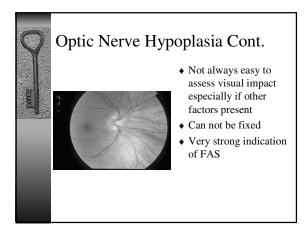
Optic Nerve Hypoplasia

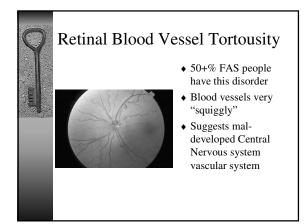


- ♦ Found in 50+% FAS
- Underdeveloped optic nerve
- Part of the underdeveloped brain
- ◆ Almost always reduces the vision
- One or both eyes













Summary on FAS and eye structural abnormalities

- ♦ The presence of a characteristic eye anomaly with at least one other factor in the absence of a chromosomal defect (Down's, Fragile X, etc) or an endocrine dysfunction is almost patho-mnemonic for an embryonic insult.
- ◆ 2 characteristic eye anomalies are almost never present in normal children, chances less than 1/100,000



Eye Health Problems

- Only two are more prevalent in FAS people than others
- Higher susceptibility to surface eye infections
- Congenital cataracts (Usually does not effect vision)





Amblyopia

- ◆ Defined as a lowering of visual acuity despite the best refractive correction and a lack of pathology or structural problems
- ♦ AKA "Lazy Eye"
- ♦ It is an active neurogical process in response to unacceptable visual problems such as double vision, confusion, deprivation etc.





Amblyopia Cont.

- Deprivational and strabismic Amblyopia most common with FAS
- ♦ Deprivational Amblyopia usually from uncorrected astigmatism in FAS and can effect both eyes
- ◆ If a child has significant refractive error (and FAS children often do) the earlier you can correct it less chance the Amblyopia will develop and the less severe it will be.



Amblyopia Cont

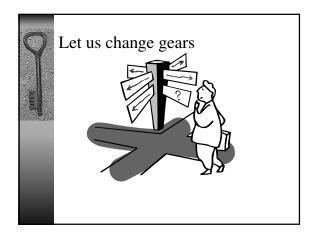
- ◆ Strabismic ambyopia results when the eyes don't line up and double vision is the result.
- Visual system attempts to ignore the information from one eye to avoid confusion ("which image is 'real'"?)
- ◆ This is a neurologically active process and takes away already limited resources of a damaged brain



Amblyopia Cont.

- ♦ Can usually be effectively treated if caught early.
- ◆ The later the treatment starts the less successful the treatment will be and the more guarded the prognosis
- ◆ This is very critical in FAS children as they already have limited neurological resources

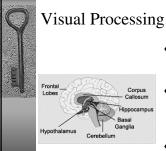






Visual Reactions and Processing (Visual Perception)

♦ Ability to make sense of the visual world, combine visual information with other senses and functions, and use this information to effectively interact with the world.



- Huge amount of brain area used for visual processing
 - ◆ Dominant sense, 70% information comes through eyes in normal adult
 - ♦ Eye- Q test



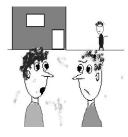


Vision is often not as dominate in FAS people

- Visual information can often be confusing and inconsistent and not matched up with other senses (SI)
- ◆ Increased reliance on tactile information
- ◆ University Scrub story
- ◆ Non-fitting clothes thought experiment
- Straw and stick
- Ball catch



 "Excuse me sir, but my depth perception is off. Is that a 6 inch guy on your head or is he far away?"

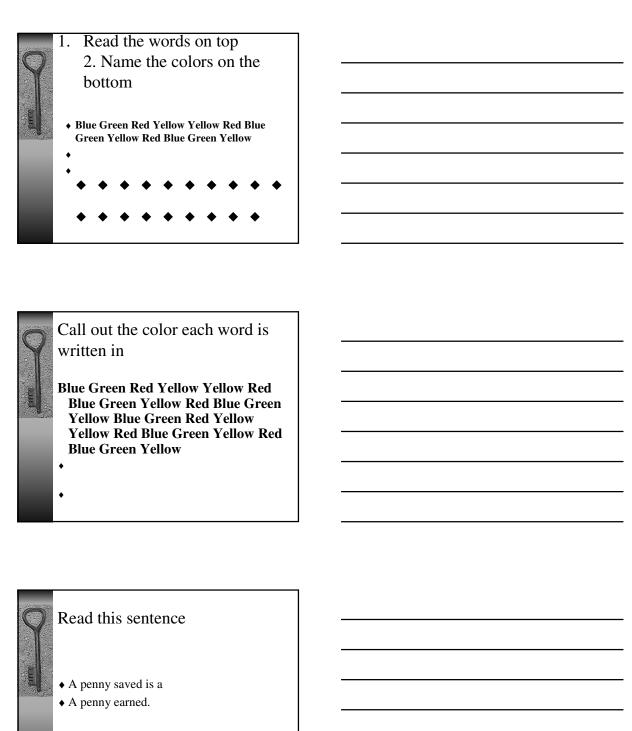




The Stroop Test

- ♦ Simulates visual attention problems
- ◆ Creates a visual mismatch problem for the visual system
- ♦ This can happen every day to FAS people



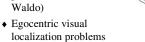






Visual Attention Problems Result

- Will want to touch everything
- ◆ Figure ground problems (Where's Waldo)







Ego Centric



Uncorrected ocular problems can make these problems even worse

- ◆ Treatment of these problems is at this time complex, some what controversial, and often involves concurrent cognitive therapy.
- ◆ Multi-disciplinary team probably has the best chance of making a difference



Some parting thoughts.

- ◆ Please try and include an eye doctor who understands FAS in your diagnostic and treatment teams.
- ◆ Many of the visual disorders found with these children can be treated.
- ◆ There are great opportunities for multidisciplinary research
- ♦ Prevention is still the best intervention

<u> </u>	 	





If you want an eye doctor on your team ask him or her;

- ♦ Is a significant part of your practice dedicated to children's vision?
- ◆ Do you have special equipment and techniques to examine people who have a hard time with verbal responses?
- ◆ Are you familiar with the ocular and visual complications of FAS?
- ◆ Are you willing to communicate your findings (with permission) to our team?



Quote(s)

- "Every child is gifted, it's just that not all of them open their presents at the same time" (unknown author)
- ◆ To which I would add "... and some of us (them) get more of a kick out of the box than the toy"
- ♦ Thank you



Diagram and photo credits

- ♦ FAS web sites
- ◆ Harvard Medical School
- Nova Southeastern University
- Norton Sound Health Corporation
- C. Jaworski's personal collection
- Dr. Allen Kabat
- ♦ Dr. Shannon Farr
- Grey's Anatomy on line
- ◆ Yellow Void cartoons
- If I forgot anyone I am sorry

FAS Summit 2002

the Eye and Visua	al System (FE	33)———		
Notes				



Community Based Support Services for Women Affected by FASD who Exhibit High-Risk Sexual Behavior

Presenter

Rebecca L. Bosek, MS, LMFT, LPC

Clinical Director

Center for Psychosocial Development

Megan S. Wilts, MS

Clinic Coordinator

Lisa K. Terwilliger

Clinic Coordinator 2210 Arca Drive Anchorage, AK 99508

(907) 258-5026

email: atrlb@uaa.alaska.edu

Abstract

High-risk sexual behaviors represent one of the least understood and most challenging behaviors for families and service providers. This workshop discusses a collaborative effort to provide comprehensive services to a group of women who are developmentally disabled (many who have FASD) and who have mental illness. Also, some of these women display inappropriate sexual behaviors or sexual offending directed against others. Key components of the approach include risk assessment, skill development, risk management support planning, specialized clinical case management, and supervision and monitoring strategies. Participants will learn specific tools and strategies to use with people with FASD.

Notes			



who Exhibit High-Risk Sexual Behavior (FB4)————————————————————————————————————				
Notes				



If it's a Standard Deviation, Will it Bite? Understanding your Child's Psychological Assessment

Presenter

Tamara Russell, Psy. D.

Pediatric Psychologist Southcentral Foundation 4320 Diplomacy Drive, Suite 1500 Anchorage, Alaska 99508-5925 (907) 729-4253

email: tlrussell@anmc.org

Abstract

Parents of children with FASD often are called upon to navigate a complex and sometimes overwhelming system. One aspect that can make the process seem overwhelming is not understanding the language, which is used to discuss the child. This presentation will provide an overview of psychological testing concepts and what they mean in the context of developing a special education plan for real children with individual needs and dreams.

Notes			



Presenter: Tamara L. Russell, Psy.D.
Pediatric Psychologist

Southcentral Foundation FAS Diagnostic Clinic

Overview: Parents of children with Fetal Alcohol Spectrum Disorder (FASD) often are called upon to navigate a complex

system to obtain the services their child might benefit from. One of the things that may make the process seem overwhelming is not understanding the language used to discuss the child. This presentation will provide an overview of psychological testing concepts and what they mean in the context of developing a special education plan for children with individual needs and dreams.

Objectives:

- 1. An understanding of the vital role the parent/caregiver of a child with FASD can play in the development of the child's special education program. This will include information on explaining to the school your concerns and your child's unique needs.
- 2. A framework for understanding test results and how all those numbers might explain a child's strengths and weaknesses. Also, how test result numbers fit with special education terms and categories.
- 3. Ways to integrate your family's core values and your child's personal definition of success, personal hopes and dreams with the test results to produce school-based goals and interventions that fit your child.
- 4. Five practical suggestions to increase your confidence in the IEP meeting.

Step 1: Getting Started

You know your child had prenatal exposure to alcohol or maybe other teratogens (any substance that interferes with normal prenatal development and causes one or more developmental abnormality in a baby). He or she is also struggling in school or having problems with behavior or attention. You are willing to advocate for your child but the process seems intimidating. It might be easy to believe that the school professionals know exactly what to do and you don't have anything to contribute to the process. But that is not true. The school professionals may have the expertise in reading instruction, developing behavior plans or giving formal tests to children, but you are the expert in your child's strengths and challenges. Working together, you and the school can make a powerful team to provide the support and services your child needs to reach his or her personal definition of success.

Before you approach the school, it may be helpful to do a quick review of things outside of school that may impact your child's learning ability.



- A. Is there a sense of stability in your child's life? Does he or she go to school each day ready to learn? The following home factors can make a big difference. Most families find they need to keep adjusting or working on these issues as children mature or family situations change. Please remember, however, that if you need help with any of these, your child's school or school district will have someone you can go to for advice or support in these areas.
 - 1) Plenty of sleep -- Children who have a consistent, regular bedtime and get enough sleep learn and remember more easily. They are also less likely to have problems with their behavior. Children from 6-10 years of age usually need at least 10 hours of sleep per night, those ages 10 to puberty need about 9 ½ hours, and teens need about 9 hours. Having a consistent bedtime is a key in helping children go to school well-rested and alert.
 - 2) Good nutrition The brain and body work better with good food. Check the amount of sugar and caffeine your child is consuming because both of those can contribute to problems with concentration and hyperactivity. Your child's physician is a good person to discuss this concern with.
 - 3) A happy, supportive home Children who live in a safe, loving home tend to do better in school. Children who are exposed to abuse, domestic violence or lots of anger at home often have a harder time with learning. Please ask for help for your family if this is an issue in your home.
 - 4) A home that values learning Your positive view of school and the joy you take in learning even difficult new things is a wonderful gift you can share with your child.
- B. Is your child's health as good as it can be?
 - 1) If glasses are needed, make sure your child has them and wears them regularly.
 - 2) Has your child had a recent physical examination by his or her doctor? Sometimes children do poorly in school because they have a chronic health problem. Talking with your child's doctor about any learning or behavior problems the child might be having will help clarify this.

Step 2: Explaining Your Concerns to the School

Sometimes it is easy to believe the school doesn't hear you when you don't speak "Educatoreese." Doing your own "homework" before you talk with the school will help.

- A. Provide specific examples of the problem. Tell how often it happens, when it happens, and how the problem is hurting your child.
- B. Use your own words and try to be brief.
- C. Put your request for an assessment in writing. At the end of this handout is a sample letter you may want to use.



Here is a chart that will help you plan what you want to say.

Area of Concern	The specific problem your child is having.
Motor Skills	
Language	
Learning & Memory	
Behavior	
Emotions &	
Friendship Skills	

Here are some common school-based problems children with FASD may have. While many children have more than one of these problems, others may have only one or two.

Motor Skills

No hand dominance by age 6
Awkward pencil grip
Still prints but is older than age 8
Works with tongue out
Poor posture, always slumped or leaning on things
Clumsy, poor balance, runs into things or people
Often invades other children's physical space
Always fidgeting, rocking or moving
Tremors

Language Skills

Long pauses before responding
Frequently uses non-specific words (thing, this, that, etc.) instead of the names for items
Gestures or uses sounds instead of words
Not 100% understandable to an unfamiliar listener by age 4
Can't identify rhyming words
Doesn't hear the difference between similar sounding words (wheel/whale, cat/cap)
Can't tell a story with a beginning, middle or end Adds details that didn't really happen
Talks a lot but the language is "fluffy"
Is unable to stay on a topic someone else introduced

Everyone says they "just don't get it"

Learning and Memory

At least 6 months behind grade level
Makes the same mistake over & over
Can only remember one step in
directions
Claims to have forgotten what was
learned yesterday
Poor general knowledge base
Can't figure out what to do next

Emotions & Behavior

Gives up easily, won't try new things
Impulsive
Easily distracted
Immature
Always moving
Sad or withdrawn
Anxious
Easily frustrated, quickly angry
Makes poor choices



Step 3: Planning the Assessment

As a member of your child's education team, you can be involved in this step of the process if you let the school know you would like to be.

- A. Decide ahead of time how much of your child's psychosocial history you would like the school to have access to. Factors that could impact a child's emotional readiness to learn may include the following items. You do not need to share details with the school, just the basic fact that the child has these issues in his or her history.
 - * pre-natal alcohol exposure
 - * a history of chronic ear infections
 - * accidents
 - * a history of frequent moves
 - * a history of abuse

- * prematurity
- * head injuries
- * serious illnesses
- * multiple caregivers
- * major losses
- B. Assess in all the areas of suspected disability Because children with FASD often have mild deficits in lots of areas, the evaluation may need to be fairly extensive. It is important to remember that multiple mild problems can add up to a greater disability than just one fairly big problem. Areas you may want to request the school to assess could include:

Cognition (Intelligence) Attention
Executive Functioning Learning Style

Memory (visual & auditory) Motor Skills (fine and gross motor)

Academic Skills (ask for a diagnostic evaluation of areas of weakness)
Language (articulation, language skills, phonemic awareness, pragmatics)

Adaptive Behavior

General Behavior and Emotional Control

C. In planning the assessment, discuss with the school-based testing specialists how cultural or environmental concerns might be addressed.

Step 4: Understanding All Those Numbers

The specialists who tested your child should be able to explain the results to you in ways that make sense to you. If it would be helpful for you to have a translator because English is not your primary language, please let the school personnel know several days before you meet with them so they can have one present.

You may bring a friend, or anyone else you choose, with you to the meeting. It is important, however, to let the school know ahead of time who is coming with you.

If big meetings with lots of school personnel are overwhelming or intimidating for you, ask to initially meet with just the testing specialist and possibly your support person to review the test results. Even when you know that your child is struggling, it is sometimes hard to hear how serious the problem may be. Learning this information in a smaller meeting may feel much more supportive for you.



- A. What is an IQ and how does it apply to your child?
 - 1) Full Scale IQ
 - 2) Verbal IQ
 - 3) Performance IQ
 - 4) Subtest scatter
 - 5) Intelligence classifications
 - 6) Multiple Intelligences
 - 7) Potential long-term implications of your child's score.
 - school and learning
 - job skills
 - independence
 - friends and family

Classification	IQ Range	Percent of individuals with the same classification
Very superior	130 and above	2.3%
Superior	120-129	6.9%
High Average	110-119	16%
Average	100-109 90-99	49.6%
Low Average	80-89	16%
Borderline	70-79	6.9%
Mentally Retarded	69 and below	2.3%

- B. What are achievement scores and what do they tell you?
 - 1) Standard score
 - 2) Grade equivalent
 - 3) Age equivalent
 - 4) Standard deviation and percentile rank
- C. Discrepancy between ability and achievement
 - 1) How this impacts eligibility determination for the learning disability category.
 - 2) Choosing the right numbers to figure this score
 - 3) Working up to potential
- D. Other factors to add to the equation
 - 1) Visual versus verbal memory skills
 - 2) Auditory processing or language problems
 - 3) Difficulty with attention and hyperactivity
 - 4) Problems with depression and anxiety
 - 5) Adaptive behavior deficits



C.	Compare where your child is performing now with where you and your child hope he/she will be as an adult. What are three key areas the school can help with? 1)
	2)
	3)

D. Combine all this information into several goals or interventions you would like to have your child focus on this year.

Step 7: Meet with Confidence

From the list developed in this workshop session, select five strategies that will help you feel confident and ready to be a strong advocate for your child as you work with the school

school.

2.

4

5.

-Good Journey -



es		Assessment	
<i></i>			



Receiving a Diagnosis of FAS in your Child: Becoming an Educator and Activist

Presenter

Kathleen Tavenner Mitchell, MHS, LCADC

Program Director/National Spokesperson National Organization on Fetal Alcohol Syndrome (NOFAS) 216 G Street, NE Washington, DC 20002 (202) 785-4585

email: Mitchell@nofas.org

Abstract

Receiving a diagnosis of FASD can be devastating and the grief process is natural. Using the anger, sadness and blame to fuel community advocacy transforms pain into positive action. Ms. Mitchell, a biological mother of an adult child with FAS will share her experience with both the process and the pain. The last section of the workshop will focus on educating others, developing a plan and community building.

Notes			



Receiving a Diagnosis of FAS in your Child: Becoming an Educator and Activist (FB6)————————————————————————————————————				
otes				



S.T.A.R.: An Alaskan School's Response to FASD

Presenter

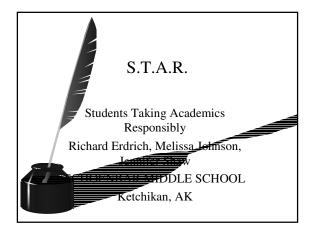
Richard Erdich, Principal
Melissa Johnson, Teacher
Jennifer Shaw, Instructional Aide
Schoenbar Middle School
217 Schoenbar Road
Ketchikan, AK 99901
(907) 247-5138
email: erdrichr@kgbsd.org

Abstract

Schoenbar Middle School will present on its S.T.A.R. program (Students Taking Academics Responsibly). The S.T.A.R. program was tailored to meet the social, emotional, and learning needs of students who were struggling academically and at risk for repeating a grade or dropout. Through an innovative collaboration with the Dept. of Education & Early Development, Schoenbar infused its S.T.A.R. program with interventions and teaching strategies proven effective in supporting students who have been prenatally exposed to alcohol. The school principal, the program's classroom teacher, and classroom aide will overview the program's uniquely supportive classroom learning environment. The Schoenbar staff will highlight the program's classroom accommodations, its structures, routines, how it minimizes transitions, community response to the program, efforts to make it sustainable, and more. This workshop will provide teachers and parents with practical and realistic tools to enhance learning and to improve the educational experience of students with prenatal alcohol exposure.

Notes			





MISSION

> TO PROVIDE A DIVERSE EDUCATIONAL PROGRAM FOR STUDENTS UNABLE TO COPE WITH THE DEMANDS OF A TRADITIONAL MIDDLE SCHOOL.

> TO GET HELP FOR STUDENTS WHO HAVE HAD LITTLE SUCCESS AS 5TH, 6TH OR 7TH GRADERS,

TO ADDRESS THE DROP-OUT ATTE OF STRUGGLING STUDENTS WHO TRANSTON FROM ELEMENTARY TO MIDDLE SCHOOL AND EVENTUALLY TO THE HIGH SCHOOL.

HE-ROVIDE A QUALITY EDUCATION IN THE LEAST RESTRICTIVE AND MOST NORMATIVE ENVIRONMENT.

WHAT THE PROGRAM LOOKS LIKE

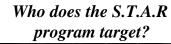


- □ The program is designed to provide a self-contained classroom for up to 20 students.
- Full time instructional aide.

teacher ratio.

Opentunity to develop and provide an excellent individualized education.







✓ Students who are 1 to 2 years behind grade level



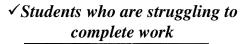




✓ Students who are failing classes in basic areas









✓ Students with low basic skills



✓ Students not turning in homework





S.T.A.R. Demographics

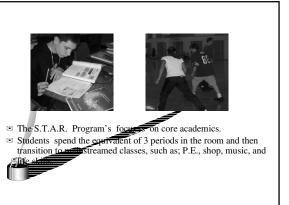
■ 7TH GRADE ■ 8TH GRADE

⊠ Gender
 ⊠ Gender

■ 12 boys 8 Girls ■ 15 Boys 2 Girls ■ 60% to 40% ■ 88% to 12%

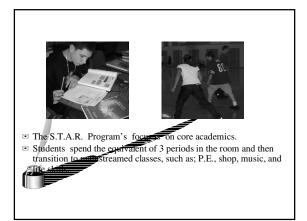
■ Ethnicity
 ■ Ethnicity

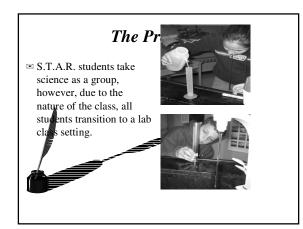
■ 1 native 9 Non-Native 14 Native 3 Non-Native



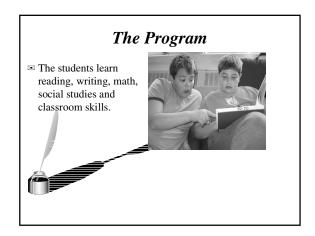
The Pr S.T.A.R. students take science as a group, however, due to the nature of the class, all students transition to a lab class setting.

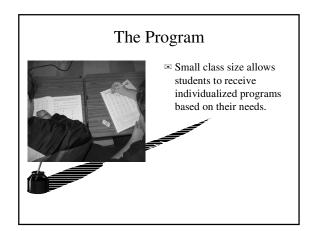


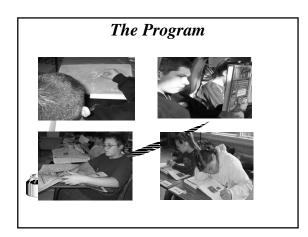














The Program



☑ Our intent is to help students become as involved in the middle school environment as possible, while insuring addemic success and growth.

Our Goals



Our Goals



™ To address the educational needs of a group of students in an alternative learning environment



ENVIRONMENTAL ACCOMODATIONS

- **■** BEAN BAGS
- **IMEGATIVE CLUTTER**
- **IM** CHALK BOARD
- **I LIMITED**
- **IM** DRY ERASE
- DISTRACTIONS
- ☑ PLAY DOUGH
- **I** NO BELLS ■ PAPER ON HALL
- **IM** STUDY CARRELS
- NDOW
- H AD PHONES
- BLANKETS
- SNACKS AND DRINKS
 LIGHTING

Environmental Accommodations



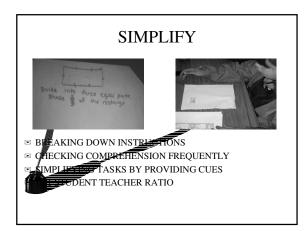
ROUTINE

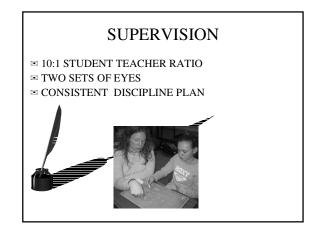


- SCHEDULE BOARD
- **OPENING ACTIVITIES**
- CLOSING ACTIVITIES
- ${f iny STRUCTURED}$ DISCIPLINE
- POINTS_AND TICKETS
- PREFARATION FOR
 DEVIATIONS FROM
 ROUTINE



ORGANIZATION SECOLORED FOLDERS PLANNERS BOXES MATERIALS IN ROOM SEATING AGRANGEMENT

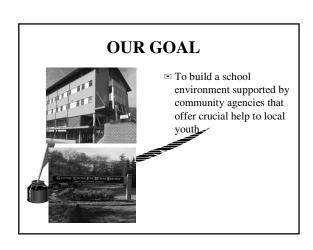






Our Goals To decrease the drop-out rate of students as they transition to high school. Itelp students we fun and success in learning.







FUTURE VISION



It doesn't end here! Schoenbar Middle School graduates 8th mile students from it's S.T. A. R. program with the attorn that these students have four more years of education before graduation.

FUTURE VISION cont.



- Wastrive for sustainability
- Whope for ongoing fina a support that allows for the continuation of the program.
- We any educational component which will provide other educators, parents and paraprofessionls who want tart a similar program.

ACKNOWLEDGEMENTS



- Special Thanks!
- Connections
- Gateway Center for Human Services
- Department of Education and Early Development
- ${f ext{$arphi}}$ Ketchikan Gateway School district Board of Education



Alaska's Comprehensive FAS Project

Office of FAS

In 1998, the State of Alaska began a renewed effort to address the devastating problem of prenatal exposure to alcohol, and the resulting life-long birth defects, establishing the Office of Fetal Alcohol Syndrome within the Department of Health and Social Services (DHSS).

The mission of the Office is to prevent all alcohol-related birth defects and to improve the delivery of services to those individuals already affected by fetal alcohol spectrum disorders (FASD).

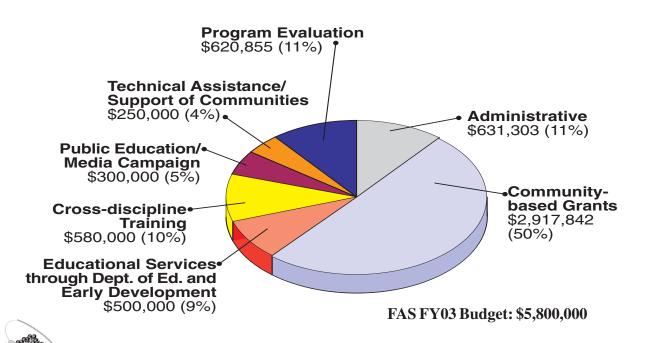
To meet this mission, four (4) primary goals have been established to address FASD across the state of Alaska:

- Prevent fetal alcohol spectrum disorders (FASD)
- 2. Diagnose children as early as possible
- 3. Improve lifelong outcomes for individuals with FASD through improved services
- **4.** Document our progress and evaluate program outcomes

Project Funding

In October 2000, with the help of Senator Ted Stevens, the state entered into a 5-year, \$29 million cooperative agreement with DHHS Substance Abuse and Mental Health Services Administration (\$5.8 million per year) to initiate a statewide comprehensive, integrated approach to FAS prevention and systems improvement. These funds greatly enhanced the initial seed grant funding the Department received in January 1998 from the Alaska Mental Health Trust Authority to initiate a renewed focus on fetal alcohol syndrome.

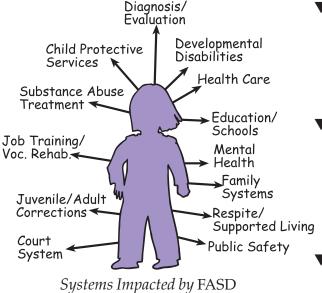
Funding for FY03 includes administrative costs (\$631,303); community-based grants (\$2,917,842); educational services through the Dept. of Education and Early Development (EED) (\$500,000); statewide cross-discipline training (\$580,000); statewide public education media campaign (\$300,000); technical assistance/support to communities (\$250,000); and program evaluation and research (\$620,855).



Prevalence of FASD in Alaska

With funding from the Centers for Disease Control and Prevention (CDC) Alaska is one of five state's who comprise the Fetal Alcohol Syndrome Surveillance Network (FASSNet), a collaboration between CDC, Arizona, Colorado, New York, Wisconsin and Alaska to develop a standardized, multi-source FAS surveillance method that can begin to provide consistent and comparable FAS prevalence rates across the country.

- ▼ Alaska has the highest rate of FAS among the five FASSNet states at 1.4 per 1,000 live births;
- ▼ Approximately 140 infants are born each year in Alaska who have been affected by maternal alcohol use during pregnancy;
- ▼ Alaska Natives have a FAS prevalence rate of 4.8 per 1,000 live births;



Project Highlights

In developing a comprehensive FASD project in Alaska our approach is community-driven with a focus on systems change and program improvement. We have placed a strong emphasis on the inclusion of families and caregivers as critical partners in our plan, as well as strong multidisciplinary partnerships with those many disciplines impacted by the effects of disabilities resulting from prenatal exposure to alcohol.

- Over 36 community-based grants have been distributed to local non-profit organizations across Alaska with focus on FASD prevention, training and educational services, improved services for individuals affected by FASD, diagnostic services, and treatment services for women at risk for giving birth to a child affected by prenatal exposure to alcohol.
- ▼ Community-based FASD Diagnostic Teams – 13 developing teams from Kotzebue to Ketchikan. Since March of 1999, when our first team diagnosis was made, approximately 305 diagnoses have been completed.
- ▼ Comprehensive FASD Training for all service providers working with individuals affected by prenatal exposure to alcohol. Curriculum development will include basic FASD information, as well as discipline specific training on strategies and interventions that work.
- ▼ Statewide Knowledge, Attitudes, Beliefs and Behaviors (KABB) Survey – beginning in April 2002 over 4,000 KABB surveys were mailed to: pediatri-



- cians; OB-GYNs; family practice doctors, public health nurses; educators; substance abuse providers; social workers; and juvenile/adult corrections workers. With over a 70% return rate, survey results will be ready for distribution in January 2003.
- ▼ Public Education/Media Campaign a statewide multimedia campaign that will include TV, radio, print ads and placement posters premiered September 9, 2002 in conjunction with International FAS Awareness Day. Two campaign themes have been developed:
 - ▲ I Have the Power to Prevent FAS aimed at women who are social drinkers and don't know that alcohol may harm their developing baby; and

- ▲ Thankfully There are People Who Will Help Her...Are You One of Them?

 Developed to reach the partners, family and friends of women who have a problem with alcohol and are pregnant, helping them find the help they need.
- ▼ Partnership with the state Department of Education and Early Development (EED) to improve the state's educational system and how it serves those children and youth affected by disabilities associated with prenatal exposure to alcohol.
- ▼ FAS Summit annual training event to provide participants from across Alaska an opportunity to increase their knowledge and understanding of fetal alcohol spectrum disorders. FAS Summit 2002 is scheduled for November 21 and 22 in Anchorage, with over 500 participants.

Office of FAS Staff

The activities of the Office of FAS are carried out by a dedicated and energetic staff of five full-time and two part-time employees.

L. Diane Casto

Program Manager

Sherrie Stears

Administrative Assistant

Heidi Brocious

Community Coordinator

Jennifer Huntley

Grants Administrator

Thea Howard

Statistical Clerk

Peter Anderegg

Publications Specialist

Ben Shier

College Intern

Victoria Collins

College Intern



Statewide FAS Steering Committee Members

Tracy Barbee

Alaska Mental Health Board.

Anchorage

L. Diane Casto

DHSS Office of FAS

Juneau

Fred Dyson

House of Representatives

Eagle River

Margaret Galovin

Aleutian/Pribilof Islands Associa-

tion, Inc.

Anchorage

The Honorable Michael Jeffery

Alaska Court System

Barrow

Loren Jones

DHSS, Division of Alcoholism and

Drug Abuse

Juneau

Reggie Joule

House of Representatives

Kotzebue

Susan LaBelle

Chugachmiut

Anchorage

Jay Livey

Department of Health and Social

Services

Juneau

Edward McLain

Department of Education and Early

Development

Juneau

Karen Pearson

DHSS Division of Public Health

Juneau

Dr. Tom Nighswander

Alaska Native Tribal Health Consor-

tium

Anchorage

Karen Perdue

University of Alaska

Fairbanks

Betsy Robson

Department of Corrections, Division

of Institutions

Anchorage

Bruce Scandling

Health & Social Services, Office of the

Governor

Juneau

Cheri Scott

Stone Soup Group

Anchorage

Rebecca Soverns

Governor's Council on Disabilities

and Special Education

Palmer

Cristy Tilden

Bristol Bay Area Health Corp.

Dillingham

Ardyce Turner

DFYS

Bethel

Dr. Karen Ward

Center for Human Development

Anchorage

Russ Webb

Department of Health and Social

Services

Juneau

Margaret Wilson

Tanana Chiefs Conference

Fairbanks

SAMHSA Project Officer

Dr. Deborah Stone

CSAP, Office of Knowledge Development and Evaluation

D 1 '11 M 1 1

Rockville, Maryland



Steering Committee Resource Staff

Diane Disanto

Commissioner's Office

Anchorage

Susan Soule

Division of Alcoholism and Drug

Abuse

Anchorage

Patti Bruce

Division of Alcoholism and Drug

Abuse

Anchorage

Pam Muth

Division of Public Health

Anchorage

Susan Merrick

Division of Public Health

Anchorage

Sheri Brechan

Division of Juvenile Justice

Fairbanks

Kathy Craft

Division of Mental Health and Devel-

opmental Disabilities

Fairbanks

Sarah Williams

Department of Corrections

Anchorage

Todd Brocious

Department of Education and Early

Development

Juneau

Keith Thayer

Department of Corrections

Anchorage

Heidi Brocious

Office of FAS

Juneau



Alaska Fetal Alcohol Syndrome Diagnostic Teams

The Bristol Bay Multidisciplinary Community FAS Diagnostic Team

The service area includes the 34 villages of Bristol Bay, which has a regional population of approximately 8,400 people. The Bristol Bay FAS Diagnostic Team can be reached at: FAS Team Bristol Bay Area Health Corporation, PO Box 130, Dillingham, AK 99576; e-mail: fasteam@nushtel.com; Phone: (907) 842-4980; Fax: (907) 842-4936.

Copper River Basin Multidisciplinary Developmental Disability Team

Referrals are accepted for anyone of any age who is having either behavior or learning problems for any reason that may indicate any kind of developmental disability. The referrals can come from the client or their families, from school personnel, from DFYS, from medical or mental health providers, or from any other service providers. The referrals are sent to Gay Wellman at the Copper River Native Association, Drawer H, Copper Center, AK 99573, or can be made by calling Gay at (907) 822-5241 or e-mail: gay@copperriverna.org

Fairbanks Fetal Alcohol Community Evaluation Service (FACES)

The role of the team is to facilitate the referral, screening, assessment and diagnosis of children experiencing difficulties related to prenatal exposure to alcohol. The team also offers information and training to community agencies and providers. The team evaluation is accomplished through the volunteer efforts of providers on the team. The FACES Team is initially targeting children between the ages of five and twelve. For children outside this age group, we discuss assessment options, provide referral assistance and advocate for resources and support services. To make a referral please contact: Sheree Dohner (451-1636) or e-mail: sheree_dohner@health.state.ak.us Fairbanks Regional Public Health Center 1025 W. Barnette Street, Fairbanks, Alaska 99701.

Kenai/Soldotna Community Diagnostic Team/Frontier Community Services

The diagnostic team has seen 79 people, ranging in age from 11 months to 43 years. Our range of service area is the entire Kenai Peninsula. Referrals can be made to Margaret Parsons-Williams for the FAS Program at Frontier Community Services. The phone number is (907) 262-6331.

The Kodiak Compass Project Diagnostic Team

The team is currently accepting referrals for the diagnostic clinic. The course of the referral depends upon the age and circumstance of the individual being referred. If the person being referred is a school aged child, the first referral should be made to the school district special education department for evaluation of eligibility for special services through the school district. KANA beneficiary clients being considered for diagnosis should be referred to Rebecca Dawn or Karen Millstein in the KANA Medical Clinic. Others may be referred directly to FAS Team Support Specialist for initiation of the process. It is expected that the clinic will see from 10 to 12 persons per year for diagnostic service It is expected that the referring agency/service provider will be an integral part of the process and assist the parent/individual with completing the necessary paper work. Please note that you can request information and education on secondary disabilities associated with fetal alcohol syndrome or fetal alcohol effect includ-

\$ummit 2002 ing other alcohol related birth defects for anyone you have reason to believe may benefit from such information / consultation. They do not have to be accepted for clinic diagnosis for this service. The service area for the Kodiak Diagnostic services includes the city of Kodiak and the village communities. For information on referrals you can contact Nancy Wells at 486-4643.

Mat-Su Valley

Mat-Su Services for Children & Adults, Inc. 5000 E. Shennum Drive, Wasilla, AK 99654 For information contact: Kim Bergey at 907/352-1200 or at kbergey@mssca.org

Northwest Arctic Borough FAS Team

P.O. Box 88, Kiana, AK 99749. For information contact: Jeanne Gerhart-Cyrus at 907 / 475-2198 ex. 25 or at jgerhardt@maniilaq

Norton Sound Health Corporation

(Nome and surrounding area) P.O. Box 966, Nome, AK 99762 For information contact: Andre Longpre alongpre@nshcorp.org 907 / 443-3495 (phone) 907 / 443-5915 (fax)

Sitka FAS Team

SEARHC (Southeast Alaska Regional Health Consortium)

222 Tongass Drive, Sitka, AK 88835. For information contact: Dyan Bessette at 907 / 966-8629 or at dyan.bessette@searhc.org

Southcentral Foundation FAS Community Diagnostic Team

Since, February of 2000, the team has been holding regular, twice-monthly clinics at Southcentral. If you would like to know more about Southcentral's community team, call Michael Baldwin at (907) 729-4251. Southcentral Foundation 4320 Diplomacy Drive #200, Anchorage, AK 99508 The phone number is 907/729-4250 (phone)

The Tongass FAS/ARBD Community Support Team

Developed and overseen by two agencies- Ketchikan Indian Corporation (KIC) and Gateway Center for Human Services (GCHS). The KIC service area includes all of the Ketchikan and Saxman communities. The pre-natal screening is targeted towards identified pregnant women. All American Indian children between birth and 18-years of age will be seen by a Medical Social Worker to identify FAS/ARBD risks. The GCHS service area includes Ketchikan and Prince of Wales Island, and can provide service to non-native clients. To make a referral, contact: Ketchikan Indian Tribal Health Clinic Gateway Center For Human Services 2960 Tongass Avenue, Fifth Floor 3050-3052 Fifth Avenue, Ketchikan, AK 99901

or call Jasmine Nelson, MSW, FAS/ARBD Coordinator at (907) 225-4061

Upper Tanana Community Diagnostic Team

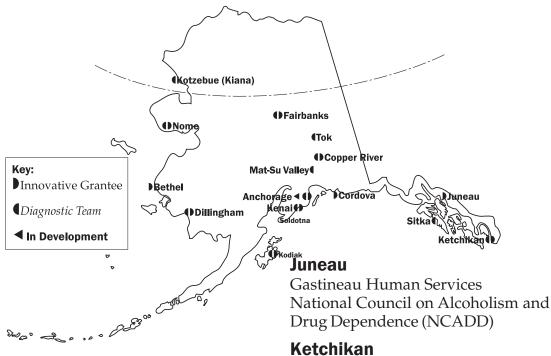
P.O. Box 459, Tok, AK 99780 For information contact: Tony Lee at 907/883-5159 or at utdcfas@aptalaska.net

The Yukon-Kuskokwim Community Team

The Yukon-Kuskokwim Community team serves one of the largest catchments areas in the state, including the community of Bethel, and 52 neighboring villages. The Y-K Team evaluates children from birth to 18 years old. To make are referral, contact the Pediatric Clinic at YKHC at (907) 543-6000, or Amy Whitt at (907) 543-6456.



Statewide Innovative Grants & Diagnostic Teams



Anchorage

Chugachmiut Hiland Motivational Interviewing Rural Alaska Community Action Program Salvation Army Stone Soup Group Southcentral Foundation Volunteers of America, Alaska, Inc. Southcentral Foundation

Bethel

The Yukon-Kuskokwim Community Team

Copper River

Copper River Basin Multidisciplinary Developmental Disability Team Copper River Native Association

Cordova

Cordova Family Resource Center

Dillingham

The Bristol Bay Multidisciplinary Community FAS Diagnostic Team Safe and Fear Free Environment, Inc.

Fairbanks

Fairbanks Fetal Alcohol Community *Evaluation Service (FACES)* Northwest Resource Associate Resource Center for Parents and Children

Ketchikan

The Tongass FAS/ARBD Community Support Team Gateway Center for Human Services **Ketchikan Indian Corporation** Tribal Health Clinic

Kodiak

Kodiak Compass Project Diagnostic Team Kodiak Area Native Associations

Kotzebue

Northwest Arctic Borough FAS Team

Mat-Su Valley

Mat-Su Services for Children & Adults, Inc.

Nome

Norton Sound Health Corporation

Sitka

SEARHC (Southeast Alaska Regional Health Consortium)

Soldotna

Kenai/Soldotna Community Diagnostic Team/ Frontier Community Services Frontier Community Services, Inc.

bummit

Tok

Upper Tanana Headstart

244

Innovative Community Grants: Category 1

Innovative Community Grants are designed to fund community-developed, innovative programs that provide for the prevention of alcohol-related birth defects and the improvement of service delivery to individuals and families affected by FAS/ARBD. These programs are designed to promote sustainable systems change within the communities and regions they serve.

AR = At risk women; P = Prevention; S= Improved Service Delivery

	Innovative Community Grants: Category 1, Grants less than \$10,000				
	Grantee	Allocation	Description		
P	National Council on Alcoholism and Drug Dependence (NCADD) Juneau, Alaska Contact Person: Dawn Miller (907) 463-3755 dmiller-ncaddj@ak.net	\$9,999	This project has purchased a FASD educational video and incorporates it into their existing Adolescent Assessment and Referral (AAR) program. AAR is an educational program serving adolescents who are referred to the program by the court for drug and alcohol violations. Grant funds will also be used to expand NCADD's existing FASD public awareness campaign.		
P/S	Cordova Family Resource Center Cordova, Alaska Contact Person: Jill Simpson (907) 424 -5674 cfrc@ptialaska.net	\$9,942	The Cordova Family Resource Center provides community education and awareness about FASD. CFRC staff purchase and distribute FASD pamphlets at community health fairs, and provide training to community agencies upon request. CFRC also provides one-on-one support to families with FASD concerns in the Cordova area.		



Innovative Community Grants: Category 2

AR = At risk women; P = Prevention; S= Improved Service Delivery

I	Innovative Community Grants: Category 2, Grants Between \$10,000 and \$50,000				
	Grantee		Allocation Description		
S	Stone Soup Group Anchorage, Alaska Contact Person: Pam Shakelford (907) 561-3701 pams@stonesoupgroup.org	\$50,000	Utilizing the Positive Behavioral Support Model, this project assists diagnostic teams, schools, families, and other agencies to build skills for caring for children diagnosed with FAS/ARBD. The model is designed and proven to work more effectively with challenging behaviors. Implementation will occur in rural communities, and information and support will be provided to other interested communities.		
AR/P	Salvation Army Anchorage, Alaska Contact Person: Joyce Guest (907) 279-0522 booth@ak.net	\$50,000	The Salvation Army, Anchorage, staffs a full-time FASD Health Educator to provide regular FAS training and awareness to high risk groups including women's substance abuse classes, parenting classes, vocational rehabilitation groups, adolescent treatment and others in the Anchorage area.		
AR	Southcentral Foundation Anchorage, Alaska Contact Person: Katie Johnson (907) 729-4955 kjohnson@citci.com	\$50,000	Southcentral Foundation has developed a child and parent advocacy project targeting women who have been discharged from SCF's Dena Coy treatment center. This grant funds the development of a system to track children of mothers served by Dena Coy to ensure adequate service delivery. The grant will fund staff training and education, will support case management, advocacy, and diagnostic referral services for children at risk for an FASD and their mothers.		
P/AR	Norton Sound Health Corporation Nome, Alaska Contact Person: Andrea Longpre (907) 443-3495 alongpre@nshcorp.org	\$50,000	This grant provides community awareness and education to Nome and the surrounding village communities. Additionally, staff work with prenatal care providers to provide case management and support to women at risk for drinking during pregnancy.		
S	Northwest Resource Associate Fairbanks, Alaska Contact Person: Aileen McInnis (907) 479-7307 amcinnis@nwresource.org	\$50,000	This grant will provide travel and/or childcare scholarships to foster parents across the state to attend training on FASD. A focal use of the funds will be on rural foster parents. Additionally, the project coordinator will work to facilitate regional trainings on FASD		
AR	Safe and Fear Free Environment, Dillingham, Alaska Contact Person: Virgina Baim (907) 842-2320 besafe@nushtel.com	\$49,940	This agency has developed a MOMSS program designed to screen and identify substance abuse problems in mothers and women of child bearing age. Grant funds will also provide these mothers and their children with support services including childcare, transportation, groups, and advocacy. Grant funds are also used to provide training for Shelter staff.		
S	Stone Soup Group Anchorage, Alaska Contact Person: Cheri Scott (907) 561-3701 cheris@stonesoupgroup.org	\$50,000	The Stone Soup Group Coordinates a statewide parent support and referral project. This grant focuses on coordinating and collecting information about FASD parent support efforts statewide, provides newsletter information to a variety of agencies, and plans to staff a toll-free hotline for parents statewide. Additionally, SSG will provide technical assistance, materials, and mini grants to communities wishing to develop parent support projects in their area.		
AR/P	Chugachmiut Homer, Alaska Contact Person: Ruthe Schoder-Ehri (907) 562-4155 ruthe@chugachmuit.org	\$50,000	Chugachmiut is funding the Chugach Region Prenatal Health Promotion Project, which provides community outreach on FASD and individual advocacy and services for pregnant women in the following communities in the Chugach region: Nanwalek, Port Graham, Seward, Tatilek and Chenega Bay. Grant funds have been used to develop village based libraries with FASD resources, and have sponsored travel and training for rural based providers.		
S	Gateway Center for Human Services Ketchikan, Alaska Contact Person: Patty Fay Hickox (907) 225-4135 pattyfay@city.ketchikan.ak.us	\$50,000	This grant allows additional staff to be trained in FAS/ARBD diagnosis at the University of Washington to broaden the scope of the Ketchikan Diagnostic Team. Additionally, funds will be used to train Gateway mental health staff, and to contract with a consultant to develop more appropriate mental health services for individuals prenataly exposed to alcohol.		

Innovative Community Grants: Category 2, Grants Between \$10,000 and \$50,000			
_	Grantee		Allocation Description
S/P	Frontier Community Services, Inc. Soldotna, Alaska Contact Person: Margaret Parsons-Williams (907) 262-6331 m_parsonswilliams@fcsonline.org	\$50,000	This project will recruit and train parent advocates to assist families through the diagnostic process and with other needed supports. The program will also train respite providers on FAS/ARBD issues, purchase "Baby Think it Over" curriculum, and provide a stipend to daycare facilities to support training and additional staff required for the provision of services for FAS/ARBD affected children in the daycare setting.
AR	Ketchikan Indian Corporation Ketchikan, Alaska Contact Person: Jasmine Nelson (907) 225-4061 jnelson@kictribe.org	\$50,000	This grant provides for the screening of all new pre-natal moms to determine if they are at risk for drinking during pregnancy. Additionally, grant funds will be used to support diagnosis and service planning through the newly established Community Diagnostic Team.
S	Gastineau Human Services Juneau, Alaska Contact Person: Janet Forbes (907) 780-3011 janlf98@yahoo.com	\$50,000	Gastineau Human Services plans to train a staff team to screen and diagnosis FASD in its adult criminal population. Grant funds were used to train GHS staff at the University of Washington. Funds will also be used to pay for case management and education personnel who will adapt case plans and services to better meet the needs of FASD clients.
S	Volunteers of America, Alaska, Inc. Anchorage, AK Contact Person: Patricia Cochran (907) 279-9634 voa-allstars@voaak.org	\$43,657	Volunteers of America, Alaska, Inc. use grant funds to expand their FASinating Families Camp to include more children affected by FASD and their families. VOA is also planning to use grant funds to host a winter camp.
P	Rural Alaska Community Action Program Anchorage, Alaska Contact Person: Monica Anderson (907) 279-2511 manderson@ruralcap.com	\$50,000	Rural CAP is developing a series of education materials for use by FASD Community teams, schools and others, focusing particularly on maternal drinking during the first 12 weeks of pregnancy. Grant funds are being used to develop an educational teaching unit, posters, and a short video directed at teenagers outlining the effects of drinking during pregnancy. Materials will be distributed in 100 rural communities across the state.
P	Kodiak Area Native Associations Kodiak, Alaska Contact Person: Nancy Wells (907) 486-9800 ilpwic@ptialaska.net	\$50,000	This grant provides for a comprehensive needs assessment of FASD services in the Kodiak area. Following the needs assessment, funds will be used to provide community-based workshops addressing FASD and providing technical assistance to the villages of Larsen Bay, Old Harbor, Karluk, Port Lions, Ouzinkie and Akhiok in developing local FASD initiatives.
S	Copper River Native Association Copper Center, Alaska Contact Person: Gay Wellman (907) 822-5241 gay@copperriverna.org	\$50,000	This grant funds the development of a comprehensive service plan for individuals and families at risk of experiencing FASD. This plan will include training service providers, hiring a case manager for FASD affected families identified by the Community Team, and the provision of home based services.
S	Resource Center for Parents and Children Fairbanks, Alaska Contact Person: Mary Lou Canney (907) 465-2866 auroraprojectak@yahoo.com	\$50,000	Grant funds will be used to develop the Aurora project, a parent education model designed by Diane Malbin, to increase the ability and awareness of parents with FASD affected children. Structured parenting classes will be supplemented by one on one support from the project manager, when necessary. The Aurora project provides support to the local FASD Diagnostic Team, scheduling parent navigators and making referrals.
AR	Hiland Motivational Interviewing Anchorage, AK Contact Person: Information Pending Contact DHSS Office of FAS for more info at 1-877-393-2287	\$149,000	This project is designed to provide screening, education and referral to high risk women lodged short term in Anchorage area correctional facilities. The project focus is on motivating women to seek treatment for their substance abuse, and increasing access to family planning and other health care resources.

The FAS Lending Library

All of the material in this guide is available for a loan period of two weeks to any Alaskan. We will gladly pay the postage to ship the material to you, however, the borrower will be responsible for the return postage. There is a maximum of 3 items per request. At the time of this printing video material are available on VHS tape only.

To order material please call the FAS Office at (877) 393-2287 toll-free or (907) 465-3033, or you may use the on-line order form at *www.hss.state.ak.us/fas/resources/*. You may wish to check the site for the most current list of available material.

Printed Material

1999 Status Update Alaska's Response to Fetal Alcohol Syndrome.

2000 Status Update Alaska's Response to Fetal Alcohol Syndrome.

2001 Status Update Alaska's Response to Fetal Alcohol Syndrome.

About Our Services

Adults Living with FAS/E: Experiences and Support Issues in British Columbia

Basic Awareness and Introduction to Fetal Alcohol Syndrome: Let's Find a Solution, Presentation Package

Beyond the Gloom and Doom NICWA

Tools for help and hope with Native People affected by FAS and related neuro-develomental disorders

Broken Cord, The

The story of Michael Dorris' search for answers concerning his son, Adam, who is FAE

Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities

Cheers! Here's to Baby!"

A birth mother's discovery of Fetal Alcohol Syndrome

Complete IEP Guide: How to Advocate for Your Special Ed Child Nolo

Conditions Reportable to Public Health DHSS DPH Section of Epidemiology

Creating Vocational Success for Adults with Fetal Alcohol Syndrome: The Yukon Experience Jon Breen

Dear World: We Have Fetal Alcohol Syndrome – Experiences of Young Adults

A guide written by and for young people with FAS/E, to help others to understand.

Effective Teaching Strategies for FAS Children: Teachers Guide

Enduring Effects of Prenatal Alcohol Exposure on Child Development

Fantastic Antone Grows Up
Judith Kleinfeld and Siobhan Wescott
Adolescents and adults with Fetal
Alcohol Syndrome

Fantastic Antone Succeeds
Judith Kleinfeld and Siobhan Wescott

FAS Summit 2001 Handbook – Beyond Diagnosis: Grief, Healing & Community Collaboration

Experiences in educating children with Fetal Alcohol Syndrome.

FAS/E and Education: The Art of Making a Difference

What parent need to know to advocate in the education system.

FAS: A Guide for Families and Communities Case studies, photos and illustrations showing the diversity of FAS.

FAS: Parenting Children Affected
Fetal Alcohol Syndrome – A Guide for
Daily Living.

FASNET Screening Tools: 0-36 months
Accesses the individual's needs for referral to determine the possibility of ARBD



-Alaska's FAS Summit 2002

FASNET Screening Tools: 0-36 months
Accesses the individual's needs for referral to determine the possibility of ARBD

FASNET Screening Tools: 10 - 13 years
Accesses the individual's needs for
referral to determine the possibility of
ARBD

FASNET Screening Tools: 14-18 years
Accesses the individual's needs for referral to determine the possibility of ARBD

FASNET Screening Tools: 19 - adult
Accesses the individual's needs for referral to determine the possibility of ARBD

FASNET Screening Tools: 3 - 5 years
Accesses the individual's needs for referral to determine the possibility of ARBD

FASNET Screening Tools: 6 - 9 years
Accesses the individual's needs for referral to determine the possibility of ARBD

Fetal Alcohol Syndrome and the Criminal Justice System

Information about people with FAS/E in the criminal justice system.

Fetal Alcohol Syndrome Diagnosis, Epidemiology, Prevention and Treatment

Fetal Alcohol Syndrome:

A resource for professionals (booklet)

Fetal Alcohol Syndrome: A Guide for Families and Communities

Fetal Alcohol Syndrome: Alaska Educator's Guide

Fetal Alcohol Syndrome: Alaska Medical Providers Guide

Fetal Alcohol Syndrome: Alaska's Guide to Prevention, Intervention and Services

Ghosts from the Nursery – Tracing the Roots of Violence

Cuts to the heart of violence committed by children.

Guidelines of Care for Children with Special Health Care Needs FAS/FAE

Identification and Care of Fetal Alcohol –Exposed Children.

Identifications of At-Risk Drinking and Intervention with Women of Childbearing Age. A guide for primary caregivers.

International Fetal Alcohol Awareness Day Kit

Kids Count Alaska 2000, Annual Report on children's health, safety and economic status

Layman's Guide to FAS/FAE
Guide with answers for FAQ's about FAS

Living and Working with FAS/E Interagency FAS/E Program

My Name Is Amanda and I Have FAE
A book (16 pages) for young children
with FAS/E, explaining FAS/E.

Needs Assessment: The Difference Game

Personal Steps to a Health Choice: A Women's Guide

Positive Behavioral Support
Stone Soup Group Training Curriculum and Workbook

Possibilities: A Financial Resource Book for Parents of Children with Disabilities

Practical Native American Guide for Caregivers of Children, Adolescents and Adults with Fetal Syndrome and Alcohol Related Conditions.
Robin A. LaDue PhD

Reaching Out to Children with FAS/FAE

Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook

Practical advice and solid information for dealing with FAS/E's lifelong effects.

Simon Says...

A book (about 8 pages) about FAS for kids, parents and teachers.

So Your Child Has FAS/E: What You Need to Know

Handbook for parents of children newly diagnosed with FAS/E.



Alaska's Statewide FAS Project-

Special Education and the Law

SSI & SSDI

Storm Rider

Craig Lesley

A novel about a foster parent raising a Native American child with FAS

Tough Kids and Substance Abuse

New drag awareness program targeted

at 'tough kids' provides practical strategies to educate about alcohol/drug issues.

Trying Differently: A Guide for Daily Living and Working with FAS and Other Brain Differences Fetal Alcohol Syndrome Society Yukon

Understanding the Drug Exposed Child Imprint Publications

Walk of Our Grandmother

Young Adults with FAS/E: Experiences, Needs, and Supports

Report of University of Victoria

Your Victory: A Happy Child Duncan

Supportive Strategies for the Staff of Children's Summer Camps and Recreation Programs.



Video

Challenge to Care, A

A staff training program for professionals working with childbearing women and their children. (38 mins.)

Channel 13 News Clip

Southcentral Foundation about FASD diagnostic clinic. (10 mins.)

Chasing Life

A Drug Prevention Program for Pregnant Women. Describes the effects of alcohol and other drugs on the lives of pregnant women and their babies. A discussion guide is provided with the video. (13 mins.)

David with Fetal Alcohol Syndrome

This video provides a unique personal look at what it's like to grow up and live with the effects of FAS, through the words and experiences of a victim and his family. (45 mins.)

Drug Babies

Discusses problems and solutions to the epidemic of the '90's: Prenatal exposure to alcohol and drugs. Explains thoroughly that proper treatment for both mother and child can help save future generations from addiction. (30 mins.)

Faces Yet to Come

Informs the viewer about FAS. Native views of spirituality, the earth and the significance of the Seventh Generation promote the well-being of future generations. Message is geared toward high school and young adults and includes a video and curriculum guide.(10 mins.)

Family Feathers

Understanding and guiding pre-school children. Tips and tools from parents, professionals and elders. (23 mins.)

FAS Conference Fall '96 North Slope Borough: Putting the Pieces of the Puzzle Together

A multiple tape training series for parents and professionals(10-12 mins. each)

Introduction

Tape 02: Manipulation – That's not what's really happening

One of a multiple tape training series for parents and professionals

Tape 03: Overloading a person with FAS/FAE is too easy

One of a multiple tape training series for parents and professionals

Tape 04: Answers to common questions about persons with FAS/E

One of a multiple tape training series for parents and professionals

Tape 05: Understanding the disability of FAS/FAE.

One of a multiple tape training series for parents and professionals

Tape 07: Abstract thinking

One of a multiple tape training series for parents and professionals

Tape 08: Connections—Causes and Effects
One of a multiple tape training series for parents and professionals

Tape 09: Time Problems

One of a multiple tape training series for parents and professionals

Tape 11: An FAS/FAE child's need to know One of a multiple tape training series for parents and professionals

Tape 12: FAS kids and expectations
One of a multiple tape training series for parents and professionals

Tape 13: Practical exercises for parents to try
One of a multiple tape training series for
parents and professionals

FAS: Everybody's Baby

Produced by parent advocate Teresa Kellerman, this video uses teen actors and the producers own adopted son to generate awareness about FAS and related conditions. (37 mins.)

Alaska's Statewide FAS Project-

FAS: Life Sentence

Discusses FAS within the context of a recent study that suggests that 20 to 25 per cent of all prison inmates may suffer from this condition. Examines how early identification and treatment of children with FAS can help prevent extreme antisocial behavior in adulthood. (24 mins.)

FAS: Quiz Show

Using a game show format, this video designed to educate children ages 9-14 on the impacts FAS can have on an individual. Lesson book included. (15 mins.)

FASCETS: Introduction

A four part training series, one hour each, for parents and professionals.

Part 1: Diagnostic Criteria: Effects of Prenatal Exposure Current information about FAS/ARND.

Research on fathers' drinking and pregnancy outcome; numerous photographs of children and adolescents with FAS/ARND are included. (60 mins.)

Part 2: Common Learning and Behavioral Characteristics

Visual model linking the neurological differences associated with FAS/ARND. Illustration of what these differences mean for children, adolescents and adults with FAS/ARND.(60 mins.)

Part 3: Behaviors and Overlapping Diagnoses
Discussion of the most common
overlapping diagnoses. The model for
providing environmental adaptations to
prevent secondary behaviors is also
included.(60 mins.)

Part 4: Barriers to Identification, Historical, Cultural, Professional and Personal Judy Cropp and Debra Evenson are interviewed and share examples of success in their personal and professional lives. (60 mins.)

Fetal Alcohol Exposure & Brain Function: Introduction

A six (6) tape overview of the University of Washington FASDPN Diagnostic Process(1:45 hour)

Tape 1: Introduction, Overview & Purpose One of a six (6) tape overview of the University of Washington FASDPN Diagnostic Process(1:45 hour)

Tape 2: Conceptual Aspects of the Diagnostic Process

One of a six (6) tape overview of the University of Washington FASDPN Diagnostic Process(55 mins.)

Tape 3: Operational Aspects of Functional CNS Assessment

One of a six (6) tape overview of the University of Washington FASDPN Diagnostic Process(1:20 hour)

Tape 4: Psychology Breakout Group
One of a six (6) tape overview of the
University of Washington FASDPN
Diagnostic Process(1:32 hour)

Tape 5: Occupational Therapy Breakout Group One of a six (6) tape overview of the University of Washington FASDPN Diagnostic Process(1:30 hour)

Tape 6: Speech Breakout Group
One of a six (6) tape overview of the
University of Washington FASDPN
Diagnostic Process(1:45 hour)

Fetal Alcohol Syndrome and Effect -Stories of Help and Hope

Provides young people, parents and others with the facts about FAS/FAE. Through these stories from professional, parents and adoptive parents, we can all to understand the effects of alcohol abuse on children and the importance of getting help. (45 mins.)

Healthy Challenges, Traditional Choices
A documentary of the YukonKuskokwin Delta region in Alaska.
Focuses on community experiences,
feelings and response to FAS and related
conditions. (39:30 mins.)



Heartbeat Alaska

Alaskan Documentary about FASD in Alaska. Two shows featuring Alaska's community efforts related to FASD.(45 mins.)

Helping Families – Helping Children Excellent video for parents of children with FASD. Practical skills and tools. Discussion and model. (28 mins.)

Helping Families – Helping Children 2
Specific strategies for parents of children with FASD in a variety of life settings.
(Home, school and community) (29 mins.)

Journey Through the Healing Circle: Tape 0: Introduction

Training Series of four videos, books and CD's, that demystify FAS/FAE using Native American storytelling format that reaches across all cultural and generational lines. (20-30 mins. per video)

Journey Through the Healing Circle : Tape 1: The Little Fox

This story portrays a mother and father fox and their young daughter fox who has FAS. Focus is on ages birth to five.

Journey Through the Healing Circle: Tape 2: The Little Mask

This story portrays two young raccoons with FAS/FAE who are left to fend for themselves after losing their parents in a tragic alcohol related accident. Focus is on ages six to eleven.

Journey Through the Healing Circle : Tape 3: Sees No Danger/Wanders Afar

This story portrays two young bears with FAS/FAE who meet, fall in love and must fend for themselves after leaving home at a young age. Focus is on ages twelve to seventeen.

Journey Through the Healing Circle : Tape 4: Travels in Circles

This story portrays a young puffin with FAS/FAE who is left to fend for himself after losing his parents in a tragic alcohol related accident. Focus is on eighteen to twenty-two.

Last Call: The Sobering Truth About FAS/FAE

To educate women who are pregnant or
may become pregnant, about the risks
associated with drinking alcohol during
pregnancy and motivate them to give
their unborn children a chance at a
normal and healthy life. (27 mins.)

Last one Picked... First one Picked on
Every child experiences embarrassment
or rejection in social situations. Richard
Lavoie, learning disabilities expert,
explains why this happens and what
teachers can do to help children improve
their social skills. (68 mins.)

Mother's Choice, A

examines the root causes of FAS for the perspective of Aboriginal mother. The video focuses on a FAS support group whose members provide strong messages about consuming alcohol while pregnant. The video is aimed at aboriginal men and women who are thinking about having a child, but may still be dealing with their addiction problems. A "Discussion Guide" is provided on the inside cover. (27 mins.)

Parents Journal – Preventing & Prevailing: The Challenge of Fetal Alcohol Syndrome

Helpful parenting information, tips and experiences for parents and caregivers of children with FAS. Developed by Tlingit & Haidi Head Start of Juneau. (14 mins.)

Precious Gift

Role playing teenagers, learning about the dangers of drinking during pregnancy. (17 mins.)

Redefining Success: Raising Children Exposed Prenatally to Alcohol (28 mins.)

Remembering What We Know

Native theme speaks about universal values of caring for the next generation and the danger of FAS. Message is geared towards grades 6 to 8 and



Alaska's Statewide FAS Project—includes a video and curriculum guide.(12 mins.)

Sacred Trust

Individuals of various Native American Nations present messages that encourage pregnant women to say "NO" to alcohol. (14 mins.)

Sebastian: An Extraordinary Life (FAS)

The story of a young boy suffering from FAS sends a powerful message to expectant mothers. (28 mins.)

Straight from the Heart

Stories of Mother recovering from addiction. A motivational program for and about women with histories of substance abuse. (28 mins.)

Students Like Me

describes and depicts classroom intervention strategies that have been found to best support child with FAS. (39 mins.)

Understanding the Drug-Exposed Child

Approaches to behavior and learning. (26 mins.)

Women of Substance: Tape 1

Follows several addicted women as they struggle to rebuild their lives. (60 mins.)

Women of Substance: Tape 3

Public awareness video introduces the complex issues related to women with addictions. Is most suitable for community meetings, targeted educational campaigns and fund raising. (10 mins.)

Women of Substance: : Introduction
Two versions of a documentary, narrated
by Joanne Woodward.

Worth the Trip

This video provides an overview of FAS and related conditions, and includes interviews and tips from experienced parents. (49 mins.)



Index of workshops on reverse.

This publication was released by the Department of Health & Social Services/Office of FAS, produced at a cost of \$11 per copy for the FAS Summit 2002 and printed in Anchorage, Alaska.



Index of Workshops

В

Behavior is Communication 139 BRAIN GYM®: Self Care for FASD Individuals, Families, Friends and Care Providers 109, 157

C

Community Based Support Services for Women Affected by FASD who Exhibit High-Risk Secual Behavior 213

Creating Change: Community Outreach and Networking 177

F

Facing the Final Countdown: The impact of FASD on Alaska's Temporary Assistance Program117

FAS 101: A foundation of current knowledge, research and Information 13

FAS is Not for Children Only: Strategies for Adolescents and Adults with FAS/E 155

FASD Education, Intervention and Research Strategies In the Justice System 129

1

IDEA: What Parents Need to Know! 53 If it's a Standard Deviation, Will it Bite? Understanding your Child's Psychological Assessment 215

K

Knowledge and Attitudes of Healthcare Professional Towards Fetal Alcohol Spectrum Disoders 89

M

Multidisciplinary Diagnosis: The Role of the Physician in a Comprehensive FASD Assessment 115

N

Noisy Diagnoses: Clarity Problems Using the DSM as a tuner in FASD 143

P

Practical Strategies for School Success for Children with FAS and Alcohol-related Conditions 169

Preventing FASD: Motivating Alcohol-abusing Women Into Sobriety 107

Prevention Through Education: Getting the FAS message out to youth 95

Providing Treatment Services to Individuals with FASD 185

Puberty and Sexuality: Ready or Not Here It Comes! 71

R

Raising a Child with FAS: Achieving a Positive Mindset 127

Risk Management Teams, Restorative Justice and Intercommunication with the FASD Community 161

S

S.T.A.R.: An Alaskan School's Response to FASD 225 School Shouldn't be Painful: Balancing the Sensory, Social, Behavioral and Academic Needs of STudents with FASD 47

Strategies for Working with Individuals Experiencing FASD and Vision/Hearing Impariments (cancelled) 175

Т

The Effects of Fetal Alcohol Spectrum Disorders on they Eye and Visual System 187

The Use of Medication for Treatment of Mental Health Difficulties: An Overview 183

Therapeutic Alliances: What Helps and What Hinders From a Consumer and Family Perspective 87

U

Utilizing a Socialization Coach: The Whys and Hows 113

Υ

Yoga and Massage for the Special Child 181

